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**Desenvolvimento de uma arquitetura escalável para
extrair metainformação de bases de dados médicas
distribuídas**

**Development of a scalable architecture to extract
metadata from distributed medical databases**

DOCUMENTO PROVISÓRIO



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Dissertação apresentada à Universidade de Aveiro para cumprimento dos requisitos necessários à obtenção do grau de Mestre em Engenharia de Informática, realizada sob a orientação científica do Doutor José Luís Guimarães Oliveira, Professor catedrático da Universidade de Aveiro, e do Doutor João Rafael Duarte de Almeida, Investigador do Instituto de Engenharia Electrónica e Telemática de Aveiro .

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Palavras Chave

texto livro, arquitetura, história, construção, materiais de construção, saber tradicional.

Resumo

Hello, here is some text without a meaning. This text should show what a printed text will look like at this place. If you read this text, you will get no information. Really? Is there no information? Is there a difference between this text and some nonsense like “Huardest gefburn”? Kjift – not at all! A blind text like this gives you information about the selected font, how the letters are written and an impression of the look. This text should contain all letters of the alphabet and it should be written in of the original language. There is no need for special content, but the length of words should match the language. Hello, here is some text without a meaning. This text should show what a printed text will look like at this place. If you read this text, you will get no information. Really? Is there no information? Is there a difference between this text and some nonsense like “Huardest gefburn”? Kjift – not at all! A blind text like this gives you information about the selected font, how the letters are written and an impression of the look. This text should contain all letters of the alphabet and it should be written in of the original language. There is no need for special content, but the length of words should match the language. Hello, here is some text without a meaning. This text should show what a printed text will look like at this place. If you read this text, you will get no information. Really? Is there no information? Is there a difference between this text and some nonsense like “Huardest gefburn”? Kjift – not at all! A blind text like this gives you information about the selected font, how the letters are written and an impression of the look. This text should contain all letters of the alphabet and it should be written in of the original language. There is no need for special content, but the length of words should match the language.

Keywords

textbook, architecture, history, construction, construction materials, traditional knowledge.

Abstract

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Glossary

CHAPTER 1

Introduction

- 1.1 MOTIVATION
- 1.2 OBJECTIVES
- 1.3 METHODOLOGY
- 1.4 THESIS STRUCTURE

Background

Oftentimes medical researchers do studies associated with diseases, such as determining the impact of a certain drug or find variables that are characteristic of certain diseases. To perform such studies and have reliable results, a great amount of data is required. To obtain that data, these researchers have to contact medical data owners to have access to relevant data that can help improve their analysis and/or findings.

With this procedure emerges several problems for the researcher such as he has to find institutions willing to share data and the process of contacting the data providers can be cumbersome. To aid in this whole process, several data hubs have been developed with the purpose of making the process of data discovery easier. One important aspect of such data hubs is that they present to the researcher meta data, which is aggregations or summaries of the original data. Metadata has the advantage that one doesn't have to deal with the anonymization process of medical records, since only summaries of the initial data are retrieved [1], [2]. With this dependency on the original data, emerges an important problem of data hubs which is, metadata can easily be outdated after a small time window. This could not raise a big problem, if the records were updated regularly, however this rarely happens, mainly because either the update process is difficult or because metadata has to be manually extracted and uploaded to the data hub. A problem that still might arise from such platforms, is those different datasets very often have different representation for the same concept or the data is organized in a different layout. The research is then hampered since either different approaches have to be taken to analyze each dataset.

The European Health Data and Evidence Network (EHDEN) [3] project has affiliations with several institutions, data sources and data custodians across the European Union (EU), which the main goal is to, within a federated network [4], harmonize their data to the Observational Medical Outcomes Partnership (OMOP) Common Data Model (CDM), which was developed by Observational Health Data Sciences and Informatics (OHDSI), a multi-stakeholder, interdisciplinary and collaborative organization that brings out the value of health data through large-scale analytics [5]. With a CDM, the problem of having different

representations for the same data across distinct data sources is solved. Researchers can now develop a single analysis method and then apply it to all gathered datasets and these methods can be optimized for this specific data model, which allows large-scale analytics. Furthermore, also improves collaborative research [5]. Still, within the scope of the EHDEN project, the project has a database catalog [6], built with the MONTRA framework [2], where data owners fill metadata about their data source manually, which brings the outdated problem already mentioned before. Additionally, whenever new metadata fields are introduced, the data owners of all data sources have to go manually update their metadata form.

To build a valuable data hub is then important to take into account how to:

- extract metadata from a data source
- upload and update the metadata on the data hub
- automatize the two processes mentioned before
- receive and display the metadata on the data hub in a way that facilitates readability.

2.1 METADATA VISUALIZATION TOOLS

It will then be explored existing visualization platforms that enhance data discovery by presenting summaries or metadata of records (data sources, datasets).

In some cases data can't be publicly available because it contains sensitive data or simply the data owner might not want to share some portions of the data, for that the tools analyzed should have privacy protection mechanisms, allowing to customize the access and manipulation of data stored.

Furthermore, considering we want to improve and assist data discovery and reuse it is important to have good data management to simplify such processes. However, humans fail to achieve the necessary processing levels with present-day scientific data. It is then important that data is provided in such a way that machines can fetch, understand, analyze and act on data. For that the Findability, Accessibility, Interoperability, and Reusability (FAIR) Guiding Principles were established which contain a series of considerations for data publishing to supports both human and machine operations such as deposition, exploration, sharing and reuse [7].

Finally, it is preferential for such a tool to be open source since the available solution might need some changes to solve our specific problem, and also it makes it possible to receive contributions from the community.

Search Method

Regarding this subject, there was already done a systematic review of several tools that fit within the current search pool. Its objective was to “identify projects and software solutions that promote patient electronic health data discovery, as enablers for data reuse and advancement of biomedical and translational research” [8]. From the final 20 systems, they captured their interoperability, what type of data they were providing and their after effect related to scientific results and improvements to better healthcare. To perform their

search they only used PubMed ¹ considering it indexes a substantially amount of health-care related work and provides a public Application Programmable Interface (API) which allows automation of the retrieval process. The programmatic retrieval was done using the Biopython framework² to query PubMed and consisted of eight steps. First, a set of publications was retrieved using the search query (“data” AND “discovery”) OR “discovery platform” applied to the publications’ titles. From the results set a filtering process was done based on their title, excluding irrelevant publications from the following steps. From each of the remaining publications, the 20 most similar publications were retrieved. The same title filtering process mentioned before was applied again to the new result set. The 5 most similar publications of each remaining publication were fetched. The title filtering process was executed, then an abstract filtering process and finally a full-text assessment. On all searches done the time window was set from January 2014 to September 2018. Moreover, publications associated with molecular biology were excluded.

Initially, the same approach was taken, now considering a time window starting in November 2018. However, after the second step, no new platforms were found. Because of that, a variation of the search method mentioned before was undertaken. The first step was skipped and some of the final tools presented on the systematic review were considered as a base set for the next steps. From the 20 presented, only 8 were used on this initial set, since some tools weren’t active or didn’t have any feature mentioned in the previous section (FAIR and data protection). Nonetheless, besides being discarded in terms of their metadata visualization features, 1 of these tools was analyzed for its metadata extraction features and 3 of them were analyzed for their metadata sharing network architecture, which will be detailed in the next sections. Coming back to the search method, the 20 similar publications for each of the 8 papers considered were fetched, and the title filtering process was done, followed by an abstract filtering process and finally a full-text evaluation. With this search method, 2 additional tools were considered, making a total of 10 tools to analyze on the section of metadata visualization tools.

eGenVar

Good data management and an organized data sharing can improve work effectiveness, and increase data analysis. One method to accomplish this is by having the data at a central repository and then provide clear and strong interfaces to interact with the data. However, because of legal and privacy rules, not all data can be stored on a public central repository. The software suite called the eGenVar [1] data-management system, allows users to report, track, and share metadata on content, origin and history of files, without compromising privacy or security. The tool can be seen as a metadata portfolio since it could be used to search data while the original files remain in a protected location. Users need to have an account to access the system and once created can immediately start using the system for search operations, however, addition, deletion and update operations over content require a personal

¹<https://pubmed.ncbi.nlm.nih.gov/>

²<https://biopython.org/>

profile. It is designed to connect current Laboratory Information Management Systems and workflow processing systems and to keep the source of data that is being processed through distinct systems at different locations. Central to the system is a tagging process that allows users to tag data with new or pre-existing information, such as ontology terms or controlled vocabularies, at their convenience. The system includes a server, a command-line client, other clients that can be developed in several programming languages and a web portal interface.

MONTRA

Data catalogs are a good way to gather and present information of different areas, however, having to build a different web-based application for each distinct situation is not feasible. To aid this creation, MONTRA [2] was proposed as a flexible base architecture for composing data integration platforms, mainly associated with the biomedical field, allowing to centralize and share data originating from several and heterogeneous sources. MONTRA can achieve this last point, by requiring the definition of a metadata skeleton within a community of data sources, which describes the original data, so different data sources following the same skeleton template will have a common representation, leading to a homogeneous representation of their metadata. Yet, it is important to salient that the system only contains a skeleton of the underlying data sources, the original data is still stored in the cataloged sources' system. The skeleton definition is an easy process any data custodian can do by saving it as a spreadsheet file and then submitting it through the application's web interface. Then, the framework allows users to view, search, modify and delete information through simple forms, where access is controlled via a Role-Based Access Control system to ensure that proper access restrictions are imposed. Also, a RESTful API is available which provides a set of programmatic endpoints which allows the creation of third-party applications on top of the framework.

This framework is in used to deploy the European Medical Information Framework (EMIF) Catalogue [9], a platform with the goal to be a marketplace where data owners can publish and share information about their clinical databases, allowing biomedical researchers to search for databases that meet their research needs. Currently, the EMIF Catalogue holds many distinct projects, combining, for example, data available in pan-European Electronic Health Records and Alzheimer cohorts. Also, as mentioned at the beginning of this chapter, this framework was as well used to develop the EHDEN portal [6], which beyond allowing the search of databases over the EHDEN network, makes available all tools and services built under the EHDEN project.

REDCap

Realizing the need for researchers to be able to secure and easily collect and share data, a team at Vanderbilt University developed Research Electronic Data Capture (REDCap) [10], which allows data collecting and metadata gathering. REDCap's data capture tools can either be structured to work as a sequence of forms that investigators fill out as they advance through their projects or as a survey meant to be filled by research subjects. REDCap allows visualizing collected data, providing views with basic statistical measures and chart visualizations, enabling the export of the data to several common formats. Several features

to help assure data quality are available, where Data Quality reports identify missing or incorrect values and outliers, validation errors and also allows the creation of custom rules to evaluate data correctness. Collected Data collected be imported using the Data Import tool, furthermore, the system offers an API to support remote insertion and fetch of data. There are also many features that enable support for various types of clinical and basic science research. REDCap also has a collaboration functionality, enabling investigators, after adding team members to a project, to assign permissions to each based on their roles and data needs.

The tool is used by the Vanderbilt research data warehouse framework [11], which consists of repositories with identified and de-identified clinical data and uses tools top of its data layer to help researchers across the enterprise, REDCap being one of them. Finally, the Ontario Brain Institute's "Brain-CODE" [12] is a platform designed to promote the collection, storage, sharing and analysis of data over several brain diseases, with the intention to understand common underlying causes of each specific dysfunction and find new ways to develop a treatment. REDCap is one of the clinical data management systems used to collect demographic and clinical data.

Data Sphere

In the late phases of a clinical trial, scientists could retrieve a great amount of usable data about the effectiveness of certain therapeutic approaches for oncologic diseases. With the decrease of cancer deaths over the years, another research paradigm is needed to find new or improve these therapeutic approaches. This lead to promote data-sharing attempts to make clinical trial data accessible to the scientific research community. The Project Data Sphere (PDS) [13] provides a platform that meets these data-sharing needs, giving the possibility to share raw data from late-phase oncology clinical trials. To share their data, data owners have to sign a data-sharing agreement that contains some extra data about the data they want to upload. If this data application gets accepts, the responsibility of patient privacy is on the data providers. Authorized users are then given the possibility to access and download all datasets made available on the platform. To become an authorized user, the platform requires that users send an application with their background and an agreement to the terms of use. Having these processes of sharing and getting data, prevents researchers from making different applications for each data set and allows having a more diverse data pool which can improve results from their analysis.

As of October 2021, the PDS website had available cancer trial data from over 200 trials including over 240,000 subjects [14].

Molgenis

For biologists to efficiently capture, exchange and exploit big amounts of molecular data, user-friendly and scalable software infrastructures are needed. For that MOLGENIS [15] was developed as a generic, model-driven toolkit to speed the development of custom big-data biosoftware applications. Biological details of each biological system can be modeled using a domain-specific language, developed using XML, not requiring extensive, technical or repetitive details on how each feature should be executed, but enabling to compactly specify what kind

of experiment database is desired. MOLGENIS can also be used to create web applications to be used by biologists, tailored to their experiments, using reusable components. The creators of MOLGENIS saw an improvement of up to 30 times in terms of efficiency when comparing to hand-writing software, besides providing several features hard to achieve by hand that were not made available by similar projects.

With the goal of developing new biomarkers and drugs, the Biobanking and BioMolecular Resources Research Infrastructure-European Research Infrastructure Consortium (BBMRI-ERIC) project [16] enables the research of basic mechanisms underlying diseases, by providing fair access to human biological samples and their associated biomedical and biomolecular data. Here MOLGENIS is used to develop their Directory 1.0 which presents an overview of the BBMRI-ERIC ecosystem with its distributed structure and helps users find biobanks of their interest.

To create a centralized research resource for Research and Development (RD), the RD-Connect [17] project associates genomic data to subject registries, biobanks, and bioinformatics software. To help RD researchers to search for RD biobanks and registries and also inform availability and accessibility on each database's content, the RD-Connect project has the D-Connect Registry & Biobank Finder tool, which is also a portal to other of their tools. One of them is the RD-Connect Sample Catalogue, which was developed using MOLGENIS, having an inventory of RD biological samples available in associated biobanks.

Cafe Variome

Data discovery applications connect data owners with data seekers and therefore promote data sharing, however, this last process can bring some complications. Cafe Variome [18] is a general-purpose data discovery platform, with the goal not to be a place to store, curate or integrate information but to provide a platform to browse through the existing data. It was developed following design principles that take into account important and emerging standards, easy to use by system administrators since is composed of a single simple software package, and also by data seekers, with flexible options allowing to customize each installation to the area of use, with a special interest on the "genotype-to-phenotype" application. To the administrator, it is given the ability to determine which data fields can be used for discovery and/or be displayed as results, and also which records are allowed to be used for discovery.

For a data seeker, the number of records that match the search term(s) are split by data source and also split into three categories:

- open access: the user is allowed to see the data present on the system.
- linked access: the user can't see directly the data stored in the system. An external data source data link or data source contact information is provided.
- restricted access: the user has to make a data request to access the data.

Mica & Opal

Enhancing the distribution of data of epidemiological studies and making research databases interoperable are some important factors to maximize the reuse of resources and, as a consequence, promoting health developments. Two open-source software tools, Opal and Mica [19],

address this by providing off-the-shelf solutions for epidemiological data compatibility, management and distribution, which were proposed by Maelstrom Research.

A centralized web-based data management system is implemented with Opal, where researchers can securely import/export a wide range of data types and formats using a simple interface, which is then converted to a common model. Nevertheless, the tool also gives the possibility to read data directly from a data source. Privacy is ensured by storing participants' identifiers on a separate database, offering tools to manage these to administrators. With data already imported, Opal web tools aids in data curations and quality control processes, enabling also for descriptive statistics computations to be automatized, presenting such on graphical charts. Taking into account all these features, using Opal over multiples studies turns out to be a strong tool to standardize their epidemiological data, which then facilitates data discoverability and metadata browsing using the other tool proposed, the Mica web portal.

Mica is used to create metadata portals for single or consortia of multi epidemiological studies, with a particular enface on supporting observational cohort studies. It is composed of several modules that allow data owners, study or network supervisors to customize detailed information about their epidemiological research datasets, studies and networks facilitating the process to organize and distribute data. After Mica is populated with study metadata, researchers can use the built-in search engine to rapidly encounter the information that they lack for their research projects. Furthermore, on multi-study instances, studies with a certain profile, that gather data of the desired health outcomes, risk factors and/or confounding factors are easily identified and gathered by users. Combining Mica with one or more Opal database(s) enables users to safely query actual study data, present on remote servers, applying searches exceeding the metadata.

Besides developing these two tools, Maelstrom Research and its partners adopted them to produce the Maelstrom Research Catalogue, a flexible collection of epidemiological studies which offer an intuitive web solution for data discovery.

BioSharing

Another interesting tool to promote data dissemination and discoverability is BioSharing [20], recently known as FAIRSharing [21], a portal of connected, informative and discoverable information about standards, databases, and journal and funder data policies in the life sciences. It acts as a “shop window” for the three types of data mentioned, detailing relations between them, presenting metrics, as standards are developed and achieved in the databases, allowing to create a historical view, showing when certain standards are created or deprecated and when updates to a database or policy happen, giving the opportunity to data seekers to check the progression of each resource. Currently, all records are manually curated, however many of them have been added and updated by community users, instead of FAIRSharing curators themselves. Users are capable of claiming records for resources they manage, allowing not only to make sure that the data on their resource is valid and updated but also to gain credit for their work. This Community curation feature, together with the coupling and

enclosure of each record into standards and databases, helps FAIRSharing become a correct and complete representation of metadata standards, databases and policies in the life sciences.

Dataverse

One of the tools that weren't present on the previous systematic review, and were found on the new search process was created by the Dataverse Project [22], an open-source web application to store, share, explore, analyze and cite research data.

Before the Dataverse Project, researchers had to choose between receiving credit for their data, by handling distribution themselves, however, it is difficult to have long-term preservation guarantees. The latter could be solved by sending the data to a third-party archive system but without receiving much credit. The Dataverse Project solves these problems: facilitates the processes of sharing data with others, also allowing to replicate others' work easily, giving the deserved credit and web visibility to all entities involved with the data being shared. It does this by presenting a Dataverse collection (a virtual archive that contains datasets, and each dataset contains detailed metadata and data files) on the data authors' website with its original look, feel and branding along with a citation for the data. Yet, that page is served by a Dataverse repository (an installation of Dataverse, which hosts multiple Dataverse collections), with institutional support, and long-term preservation guarantees.

NADA

Another tool found on the search process performed was National Data Archive (NADA) [23], a web-based cataloging application that can be used as a base structure to create portals that allow users to browse, search, apply for access, compare and download census or survey data. It was originally developed to assist the establishment of national survey data archives and is currently in use by several regional, national and international organizations.

When a NADA installation is deployed, the default catalog created is the Central Data Catalog, where all studies uploaded to NADA are visible, searchable and accessible through it. In most cases, this is enough to have the data stored and organized, however it is possible to split the contents of this central catalog into more specific collections. This brings advantages for both the users and the administrators since the former can more easily filter and search collections of surveys that are related, the latter can better distribute management responsibilities to specific administrators for their specific study area.

The NADA uses the Data Documentation Initiative (DDI) standard to represent the metadata for each study, where such documents are built outside the NADA application and then imported. Users can take advantage of such metadata by performing searches about surveys in the catalog down to the variable level.

The tool also allows to include citations at the study level, pointing to works that used the data of a certain study. These resources are convenient for researchers to see how the data have been used previously and also to show survey funders the study impact and that the data is being used for research purposes.

The level of access to the studies datasets can be controlled at the study level, allowing to have different access restrictions for distinct studies. The available access types are:

- Data not available
- Direct Access Data Files: no login required
- Public Use Data Files: login required
- Licensed Data Files: application required
- Data available in an Enclave: application required and the data is stored on the data owners site
- Data available at an external repository: data is stored on the data owners site

2.2 METADATA EXTRACTION TOOLS

Associated with some projects mentioned in the previous section, several tools and processes are relevant for the task of extracting/profiling datasets. Next are presented such tools:

Search Method

TODO describe this

search terms: metadata (extration or creation),
"metadata" (extraction or creation) from database,
extraction from database,
metadata fingerprinting a database,
metadata updating,

ACHILLES

The OHDSI project, already mentioned at the beginning of this chapter, offers a variety of open-source tools [24] that can be used on several data-analytics use cases on observational patient-level data. Such tools can communicate with several databases that have adhered to the OMOP CDM, enabling them to homogenize the analytics for different use cases. With this, instead of having to build an analysis from scratch, a standard template can be used, turning the process of building analyses easier, and also enhancing transparency and reproducibility.

One of such tools, Automated Characterization of Health Information at Large-scale Longitudinal Evidence Systems (ACHILLES) [25], can produce summaries and metadata of CDM databases. These allow for characterization and quality assessment of observational health databases. It is implemented as a package written in R ³, which executes a series of SQL queries over the original CDM database to calculate all the specific summaries, which in the context of ACHILLES, are called analyses. The result of these queries is then placed on a target database schema chosen by the user. The resulting summaries are not study-specific but can be used by researchers to explore and evaluate if the contents of databases can be used on studies that they intend to perform. However, certain summaries might reveal some information of the original data that the data owner is not willing to share or because is sensitive patient information. With this, variations of these tools are created where only

³<https://www.r-project.org/>

certain summaries are extracted from the data source, removing the process of having to filter the output of the ACHILLES. Such a tool was developed associated with the EHDEN project [26].

DataMed

Facilitating the process to find appropriate datasets is a key aspect to improve data reuse in the biomedical domain, however, it is hard to achieve due to the biomedical data complexity and volume. DataMed's [27] mission is to build a data discovery index enabling users to efficiently search and access existing datasets that are spread across several repositories.

It developed a metadata ingestion pipeline that extracts, maps, and indexes by following the Data Tag Suite (DATS) based on community input and an analysis of existing metadata from popular repositories. The DATS model mentioned is used to describe the metadata elements and the structure for datasets [28]. DataMed's pipeline was built as a horizontally scalable, message-oriented, extract-transform-load, loosely coupled distributed system, composed of a message dispatcher and one or more data processing segments. The dispatcher functions as an orchestrator by managing the data ingestion and processing pipeline through message queues. Each processing component performs operations on the data such as transformation, cleanup, and/or enrichment, saves the result to a document database and then notifies the dispatcher through the message queues. Next, a pipeline specification is used by the dispatcher to decide the next step, injecting a message on the message queue of the target consumer.

Since different data sources have distinct representations, the pipeline has to abstract retrieval modes and data formats. This is achieved by implementing different ingestors for the possible retrieval modes and data format combinations. Each particular ingestor transforms raw data into the DATS, and they make use of data iterator(s), which allows retrieving data only when necessary, in other words, data streaming, allowing to deal with the situations where the datasets are larger than the available system memory.

An interesting and important note is that there was already some work done on mapping datasets represented in the OMOP CDM to DATS [29].

Xtract

...

MetaExtractor

...

Skluma

...

2.3 METADATA NETWORK ARCHITECTURES

Considering that we have an agent that extracts or gathers metadata from a data source, it is also important to think on how they will transfer or communicate data with the interface

that clinical researchers use. Next it is presented some projects that design some sort of network architecture to retrieve data from the data owners site:

CafeVariome

Coming back again to Cafe Variome [18], it was designed to be used safely, with sensitive datasets. With this, it is often important to limit which persons can access the system and perform their data discovery browsing/queries. This leads to laboratories connecting in closed or semiclosed discovery networks with limited access. Cafe Variome offers the following network architectures:

1. hub and spokes arrangement: it has a single discovery portal where searches can be performed across all partner in the network
2. all-to-all networks: each laboratory has an individual interface over their data, that can be used by other network members
3. combination of the previous architectures

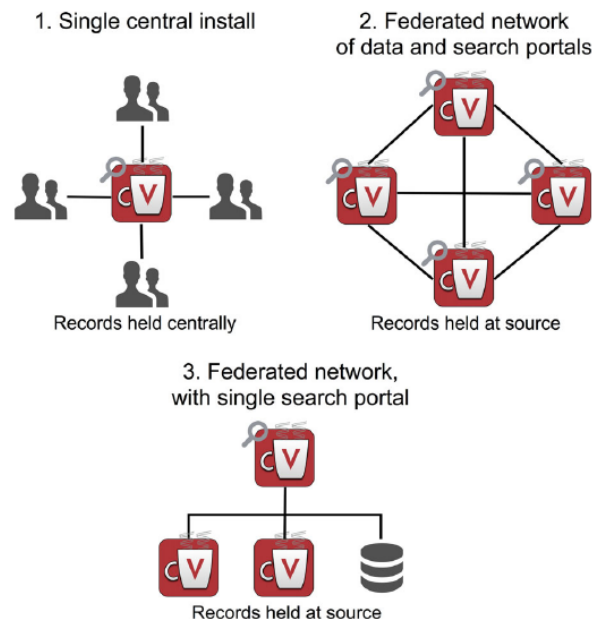


Figure 2.1: The available network architectures in Cafe Variome. Image retrieved from [18].

Despite the chosen arrangement, each node can choose to customize the access policies for specific records or fields, making them available for discovery to certain groups in the network.

GAAIN

One more tool analyzed because of its metadata sharing network its Global Alzheimer's Association Interactive Network (GAAIN) [30], in which its main objective is to organize a community for sharing Alzheimer's-related from diverse repositories around the world, where data from different medical fields are combined together, taking into account existing policies of these repositories and preserving the ownership of the data being shared.

The architecture of GAAIN contains a central server that interacts with multiple client nodes, which are installed in the data partners site (Data Partner Clients (DPC)). These

GAAIN DPCs don't gather data directly from their data partner production environment, instead, data is locally exported and transformed into a CSV file and only then loaded into the DPC. With this process a DPC will have a low footprint, not interfering with the data partners system, and also is given the freedom to the data owners to update their data when they find it convenient. To have this DPC running on the data partner's site, the only requirement imposed is to adapt current firewall configurations to allow incoming HTTPS traffic from the central server into their network. Data owners still have full control over their data, and to do so every GAAIN DPC has "on/off switch" which gives the possibility to immediately detach the data from the network.

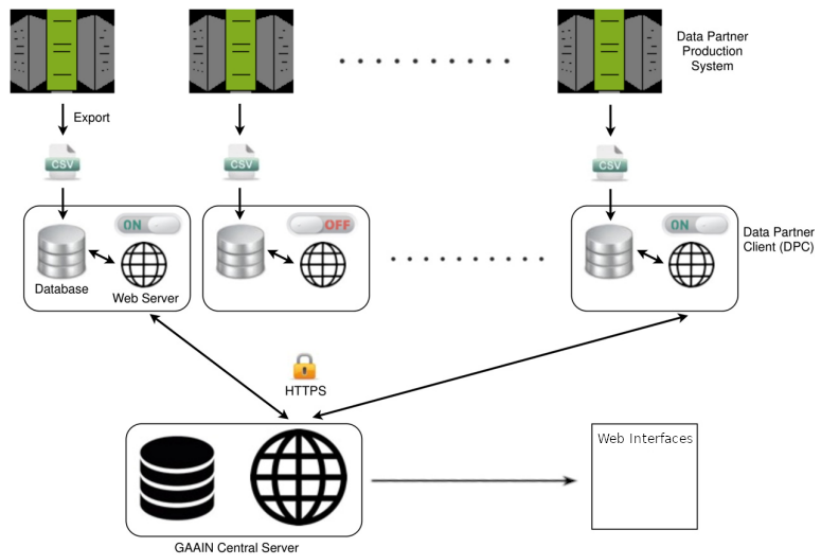


Figure 2.2: Network architecture of the GAAIN. Image created based on an original retrieved from [30].

Then, with this network architecture, GAAIN researchers can query the network through its web interfaces, which forwarded the search requests to the central server component which then queries every individual DPC. The results are sent back to the central server that aggregates them into a response to then be displayed on the web interface.

PopMedNet

With the increase of availability of electronic health information, the engagement to distributed health data research networks has risen. Popmednet [31] appears to facilitate the creation and management of distributed health networks, taking into account the demands of different data owners and researchers. The platform's adaptable architecture allows network designs that satisfy important requirements of data owners of a network, including data privacy and security requirements and network monitoring functionalities. Researchers have available a set of features that aid in the processes of finding possible data owner collaborators, finding previously carried out research and learn more about the data in the network, thus the system is going beyond of just issuing queries.

The platform is made of two components: a web-based portal for issuing research requests and managing the network, and the clients' DataMart. They communicate with each other following a publish-subscriber philosophy, which removes the need for data owners to have open ports on their systems, solving an important security concern of existing direct external access to local data. With this approach, the DataMart Client is present at the data owner's local machine, behind their firewall, and all queries from the network portal are pulled from it, instead of them being pushed through an open port. Data owners can then use the DataMart Client to review requests fetched from the network portal by analyzing its metadata such as information of the requester and the description and purpose of the request. Then it can opt to execute the query and send the results back to the network portal, keep it for additional review or refuse it. With this asynchronous approach to querying, data owners have full control of their data and all its uses, however, instead of doing these review steps manually, it is also given the possibility to automate them.

EHR4CR

Yet another project with an interesting network design to share Electronic Health Record (EHR) is the EHR4CR [32] project. It aims to create a robust and scalable platform to share data from distributed Clinical Data Warehouse (CDW), taking into account requirements and policies, such as data protection, allowing to identify patient cohorts (a group of patients that satisfy specific criteria) and to extract patient-centric data.

The access to the clinical data present at each CDW endpoint is done through three logical layers:

- Legacy system layer: specific to the CDW
- Legacy Interface layer: deals with the complexity of translating queries against the EHR4RC data model to the terminology used by the specific CDW or EHR system and also convert the results of such queries to the common EHR4RC data model.
- EHR4CR Data source Endpoint layer: exposes a standard EHR4CR endpoint interface so other EHR4CR services can easily access the CDW or EHR system's data.

Once these layers are implemented and properly working, information about the service provider is added to the central registry of the platform, allowing users to discover and browse through them.

The platform's architecture was built around the Protocol Feasibility Scenario (PFS), which retrieved aggregated results from each data source about quantities of patients that fulfill a certain Eligibility Criteria (EC), and the Patient identification and Recruitment Scenario, that has the goal of retrieving patient information with consent to further be used on research. The most important scenario to analyze is the PFS one, where makes use of three main components:

- Workbench: acts as an interface where an end-user can issue EC queries to execute on the network and see the aggregated results.
- Orchestrator: distributes the queries received from the workbench across the data endpoints of the network, joining the returned results and sending them back to the workbench.

- Endpoint: services with CDWs where the queries will execute

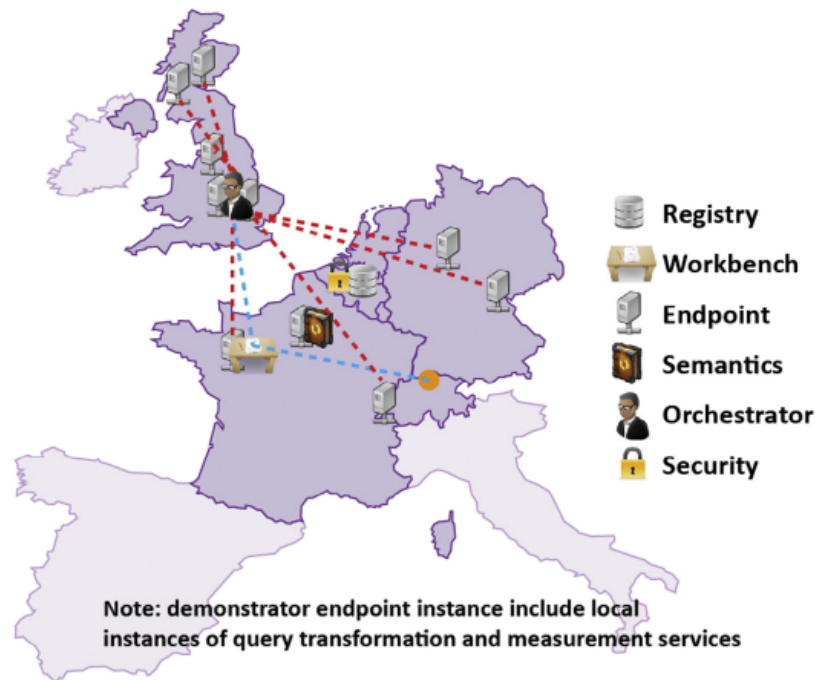


Figure 2.3: Interaction between the main services used on the Protocol Feasibility Scenario. Image retrieved from [32].

While building the platform, data owners' common security policies and firewall restrictions were taken into account by supporting the invocation of web services using dynamically configurable transport bindings. Examples of such are publish-subscribe methods that were mentioned in the previous tool, where an endpoint retrieves (pull) incoming queries instead of receiving them directly (push). This guarantees agreement to local data owners' security policies, without jeopardizing existing authentication and authorization mechanisms on end-user and web service clients.

NextGen Connect

Data owners face challenges when trying to share vital patient data quickly since institutions are pressured to keep interoperability a secure cost-effective functionality. To do so, IT administrators need solutions that allow customization and are scalable.

In a continuously changing healthcare economy, NextGen Healthcare Solutions assist in supersede these challenges by: increasing the capabilities of sharing data; efficiently combine and transfer data over multiple systems; diminish costs and satisfy urging needs with Fast Healthcare Interoperability Resources (FHIR, a standard that defines data formats and API to exchange EHR) based APIs. One of such solutions is NextGen Connect, where NextGen Healthcare's goal is to offer the healthcare society a secure and practical way to share health data.

NextGen Connect contains an Integration Engine that, like a language interpreter who translates from one language into another, translates a message represented on a given format

into another that the destination system understands. Whenever NextGen Connect receives a message from an external system, the Integration Engine perform:

- Filtering: analyses the message parameters and transfers or discards it from going to the transformation phase.
- Transformation: converts the message from its original format to the desired standard format (e.g., HL7 to XML) (Popular Medical standards supported, ex: DICOM, HL7). The tool also allows more customizable transformations by executing custom Javascript or Java code.
- Extraction: retrieve data from and send to a database.
- Routing: ensure that all messages are received by their destinations.

The components that are configured and execute the jobs mentioned above are called channels. It consists of multiple connectors which are in charge of loading the data into NextGen Connect (source connector) or loading the data to an outside system (destination connector). Each channel has exactly one source connector and one or more destination connectors. A possible configuration is to receive data over HTTP, then send the result of the configured transformations to a file and/or insert it into a configured database.

2.4 FINDINGS

Tool Name	Open Source	Visualization/Interaction		Extraction	Network
		Data protection	FAIR		
eGenVar [1]	✓ ⁴	✓ (Users + Permissions)	✓	✗	✗
MONTRA [2]	✓ ⁵	✓ (Role based)	✓	✗	✗
REDCap [10]	✗	✓ (Role based)	✓	✗	✗
Data Sphere [13]	✗	✓ (Authorized Users Only)	✗	✗	✗
MOLGENIS [15]	✓ ⁶	✓ (Role based)	✗	✗	✗
Cafe Variome [18]	✗	✓ (Role based)	✓	✗	✓
Mica & Opal [19]	✓ ⁷	✗	✓	✗	✗
BioSharing [20]	✓ ⁸	✗	✓	✗	✗
Dataverse [22]	✓ ⁹	✓ (Role Based)	✓	✗	✗
NADA [23]	✓ ¹⁰	✓ (Access Request)	✗	✗	✗
ACHILLES [25]	✓ ¹¹	✗		✓	✗
DataMed [27]	✓ ¹²	✗		✓	✗
Xtract [33]	✗	✗		✓	✓
MetaExtractor [34]	✗	✗		✓	✗
Skluma [35]	✓	✗		✓	✗
GAAIN [30]	✗	✗		✗	✓
PopMedNet [31]	✗	✗		✗	✓
EHR4CR [32]	✗	✗		✗	✓
NextGen Connect	✓ ¹³	✗		✗	✓

As we can see there is no tool that all the cheks ...

TODO closing notes

-
- ⁴<https://github.com/Sabryr/EGDMS>
 - ⁵<https://github.com/bioinformatics-ua/montra>
 - ⁶<https://github.com/molgenis/molgenis>
 - ⁷<https://github.com/obiba/mica2>
 - ⁸<https://github.com/FAIRsharing/fairsharing.github.io/>
 - ⁹<https://github.com/IQSS/dataverse>
 - ¹⁰<https://github.com/ihns/nada>
 - ¹¹<https://github.com/OHDSI/Achilles/>
 - ¹²<https://github.com/biocaddie>
 - ¹³<https://github.com/nextgenhealthcare/connect>

Metadata Visualization

Among the presented tools in chapter 2, MONTRA was our go-to mainly because of its data source-centric approach. Also, no real data is shown here, only metadata is handled within the platform, however, it still allows to impose access permissions at several levels.

This chapter will detail the key concepts of the MONTRA framework and its internal data model. After this, there will be presented a refactoring process that was done to the platform, with its improvements and flaws fixed.

3.1 MONTRA

Originally, the MONTRA framework was developed by the Bioinformatics team of the Institute of Electronics and Informatics Engineering of Aveiro associated with the EMIF project with the goal to develop a common patient health information framework with emphasis on the research topics of Obesity and its metabolic complications and Markers for the development of Alzheimer's disease and other dementias. The code is publicly available on github¹, whereby Django 1.4, a high-level Python Web framework[36], was used as a framework to develop the entire system. This framework allows to develop complete web applications, in a faster and easier way. It contains a model layer that allows specifying database tables through python classes called models, following a Object-Relational Mapping (ORM) approach, allowing to perform database queries through python code instead of Structured Query Language (SQL) queries. Django can then check if there are new models or if existing ones have changed. Such changes are then expressed through database migration files which will apply them to the database tables. Next, the developer can set custom URL patterns so specific requests are handled by a specific function of the view layer, where the business logic will be implemented. Finally, Django contains a template layer that allows building dynamic HyperText Markup Language (HTML) pages without requiring to have a separate javascript framework to do such. The developer builds the main static structure of the page and then uses a special syntax that describes how Django should display the data received from the view layer. Django also

¹<https://github.com/bioinformatics-ua/montra>

has an important form feature that allows to easily create a set of pages that allow performing the usual Create, Read, Update and Delete (CRUD) operation over the database model.

MONTRA's development started at the beginning of 2013 and ended in the middle of 2018. After this date, at the end of 2018, the framework started being used by the EHDEN project, to develop a portal to allow discovery and analysis of health data of a federated network of data sources standardized to the OMOP common data model in Europe. Currently, the project is being developed in a private repository but has intentions to make it public after the code base is more robust and well documented.

3.1.1 Communities

In the first versions of the framework, MONTRA allowed only one level of organization related to data sources, in which they could only be separated according to their skeleton that describe their original data, which will be more detailed in the next subsection. Newer versions created the concept of a Community. This allows having multiple networks of data sources on the same portal, where originally the only option was to have different installations of the framework.

These communities can be created in several ways:

1. the admin can create it through Django's admin console
2. a user can request a community to be created through a form and then the admin will receive an admin with such request
3. the MONTRA installation can be deployed in a single community mode where only one community exists, which is created on the first setup, giving the idea that there is no community concept on the platform

They also can have different access levels:

- Open: Does not require membership. Any user can access the data sources of this community
- Public: Does not require a membership however, the user needs to accept a set of terms and conditions before being able to access the data sources
- Moderated: A user has to request the community managers for approval
- Invitation: Users can only access and see the community by invite and subsequent approval

Plugins

The concept of Community also allows customization at that level, affecting only sections within that given community. One example of such customization is plugins, a way to extend the functionalities of the framework without having to deal with the base code. These plugins can either be full web applications, with different functionalities, that are linked to MONTRA through the community navigation menu or extensions that provide extra data services such as a dashboard about the data of a data source.

3.1.2 Questionnaires

As the data from different data sources is highly heterogeneous, MONTRA ensures that the data inserted within a given community follow a common structure. This structure is called a skeleton, which is represented in a form of a questionnaire with a set of questions, which can then be grouped in sections called Question Sets. It represents a set of metadata that better describes the original data of data sources that need to remain private. The skeleton schema can easily be defined through a spreadsheet, which will be more detailed on subsection 3.1.4.

Next is presented the available question types which can be used to build a questionnaire for a community

Type	Description
choice	Single choice (radio box)
choice-freeform	Single choice with an open text fields
choice-multiple	Multiple choice (checkbox)
choice-multiple-freeform	Multiple choice with and open text fields
choice-multiple-freeform-options	Multiple choice with and open text fields
choice-tabular	Creates a table with single, multiple choices or text by row
choice-yesno	Single choice with yea and no choices
choice-yesnodontknow	Single choice with yes, no and don't know choices
comment	Used to separate groups of questions
custom	Mirrors another question by its type
datepicker	Field with date picker widget
email	Text input with email validation
numeric	Numeric input
open	Text field with no validation
open-button	Text input with backend validation
open-location	Text input with autocomplete sugestions
open-multiple	Allows to record an history of a value overtime
open-multiple-composition	Allows to record an history of several values overtime
open-textfield	Same as open but a textarea html tag is used
open-upload-image	Image upload
open-validated	Text input with a regex validation
publication	A custom widget that allows to attach a set of publications
sameas	Mirrors another question by its number
timeperiod	Numeric input + select to choose numeric unit
url	Text input with url validation

Table 3.1: All available question types that can be used to build a questionnaire

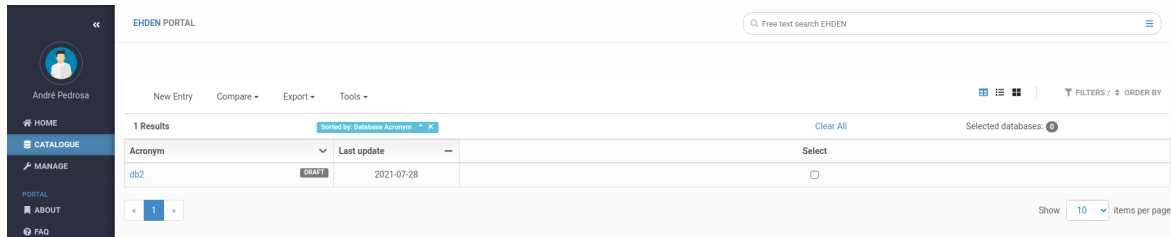


Figure 3.1: The user interface displayed after selecting a community, which shows the list of the fingerprints of the chosen community

3.1.3 Fingerprints

A fingerprint is a name given to the set of answers to the questions of a questionnaire. In other words, it is the metadata that better describes the original data of the associated data source. Data owners can start to answer the questions to build the profile of their data sources once there are communities on the platform and, these have at least a questionnaire associated.

On the list presented in figure 3.1, we can notice that the only fingerprint present is marked as draft. This is a state of the fingerprint which prevents from non-ready or non-approved fingerprints won't show to the regular community users. With this, for such users the list showed above would be empty. Fingerprints can be published depending on the chosen settings for the community. After the data source owners request to publish a fingerprint the framework allows to either automatically accept or require a community manager to accept it.

Views

In figure 3.3 it is presented the user interface where a data owner can answer the questions of a questionnaire. Each question of the questionnaire is placed under a container that can be collapsed, as is shown for question *Institution name*. However, if multiple questions are grouped, the collapsible container will affect all questions of the group. Besides the input widget where the data owner can insert its answers, the user also has some additional control buttons:

1. Allows to Hide or Show Questions that have been answered or that are empty. Besides being an interesting feature is important to note that on the last version it does not work, as clicking on the presented options will result in no visual effect
2. Allows to collapse or expand all questions or question groups containers
3. Allows the data owners to set permissions at the question set level
 - Visibility: Let plugins have access to answers data
 - Allow printing: On the fingerprints list page, showed in figure 3.1, there is a dropdown with tools, being the only one the "Print" tool (3.2). However, this feature is not correctly implemented since it calls the browser's built-int printing function on the fingerprint list page, so no actual fingerprint data will be printed. This permission ends up being useless. Additionally, if a user calls the browser's print function (e.g. hitting Ctrl+P) when viewing the data of a fingerprint, the platform will not block the action.

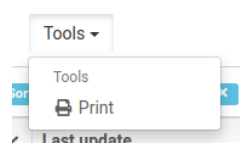


Figure 3.2: Available tools on the fingerprint selection

Figure 3.3: User interface to create a fingerprint

- Allow indexing: If the data owner allows indexing of the answers, which will allow for other users to find fingerprints based on the answers to a question of this specific question set.
 - Allow exporting: If the answers to this question set can be included on the export file of a fingerprint.
4. Enable navigation along the question sets of the current questionnaire
 5. Permits to save or cancel all the changes made to the current question set

Once the fingerprint is filled and published, a regular user can consult the metadata, which will be displayed by default in detailed view. Similar to the create view, it is presented with some control buttons:

1. Database level plugins associated with this community
2. Statistics of this fingerprint
 - Progress bar + Filled: How many questions of the questionnaire were answered
 - Hits: Number of times this fingerprint showed up on search queries
 - Unique Views: Number of users that visited this fingerprint
3. Question set controls
 - Summary: Allows to switch to the summary view (Figure 3.5)
 - Collapse & Show: The same role as mentioned for the create view
4. Fingerprint control buttons

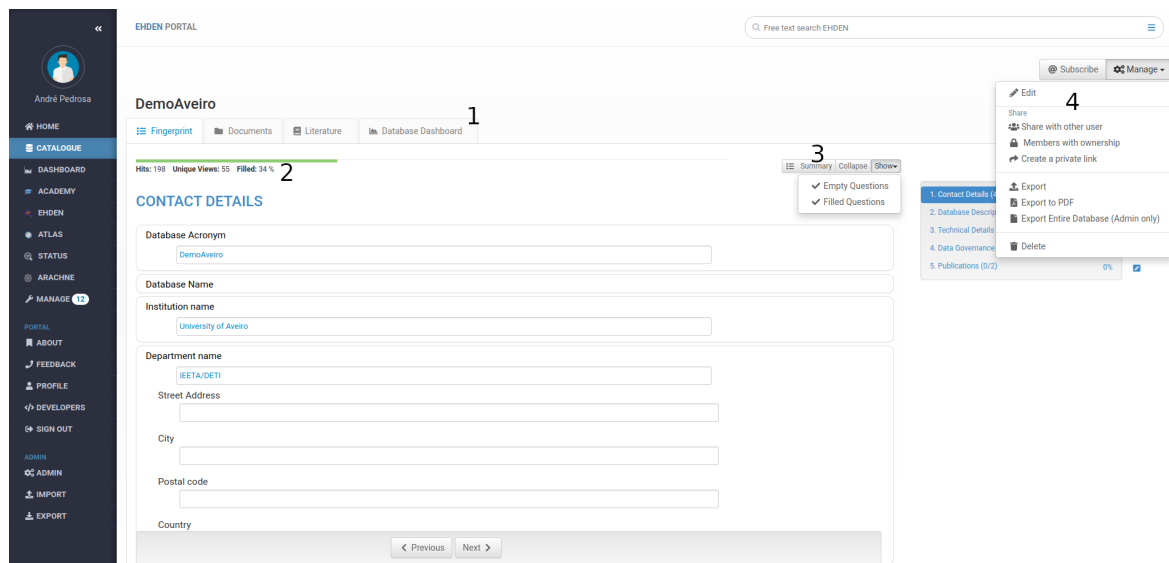


Figure 3.4: A detailed version user interface to view and analyze fingerprints

- Subscribe: Receive notifications whenever changes are made to the fingerprint answers
- Manage: Several fingerprint operations
 - Edit: Enter the edit mode
 - Share: Allows to add other users as owners of the fingerprint and also to create links that enable anonymous users to consult the fingerprint
 - Export: Different forms of export. CSV, PDF, and MONTRA format to import on other installations of the MONTRA framework
 - Delete: Remove the fingerprint from the community

On the show view, if the user enters the summary view (Figure 3.5), the user is presented with a table with three columns where each row contains the question number, name and the answer given. On this view, by hovering over an empty answer container the user can send a request to the database owner to answer the specific question.

The MONTRA framework also offers an “Advanced Search” feature, allowing to perform searches for fingerprints. The overall interface used is identical to the ones presented above, where the user answers the questions of the specific questionnaire of the community. The main difference to the other versions of the fingerprint view is that the only control buttons available are just the navigation ones, and all the questions don’t have any validation. Additionally, at the bottom of the page, it is provided to the user a way to customize the search query, allowing to create complex search criteria through a drag and drop interface, as is presented in figure 3.6.

Despite all these variations of the same view having a similar look, as some components appear on several variants, all views have a separate Django template, so there is some duplicated code across the different views. If some changes are made to a shared component, such as the side question set menu bar, those changes have to be applied to all different

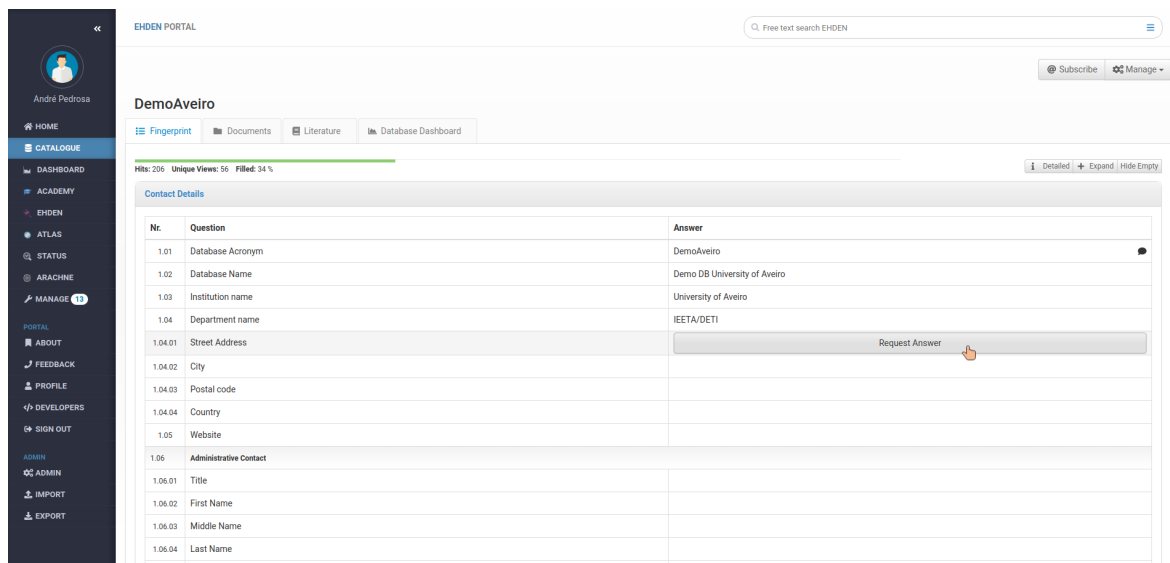


Figure 3.5: A summary version user interface to view and analyze fingerprints

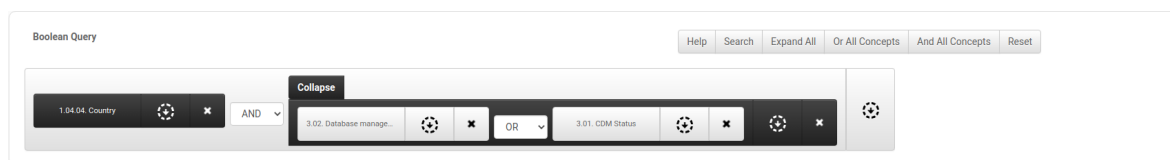


Figure 3.6: Interface to customize the fingerprint search query

templates. This can be avoided since the Django template system allows to both include a shared component into other templates and also supports conditional rendering, for example, the permissions dropdown for a question set of a fingerprint should only be rendered when the user is editing or creating a fingerprint.

These different view versions provide a valid workflow to perform CRUD operations over the metadata related to a data source, however, views that are used to insert or edit metadata of a fingerprint present several flaws related to how the inputs are validated and how they are presented to the user.

First, the validation of the user input is done on the client-side through javascript code that runs after a user submits a question set form. Subsequently, the data is sent to the backend through API calls. However, if one would use the API directly to update metadata of the fingerprint, the validation could be skipped and invalid data could be stored on the database. In some cases there might exist some validation code on the server-side, however, this brings the necessity to maintain two separate code files.

Second, there is no escaping procedure done to the user's input when it is fetched from the database which allows that Cross-Site Scripting (XSS) attacks can be easily performed and put users that consult a compromised fingerprint at risk. As an example, on figure 3.7 on the Database Name field, I added a *script* tag with code that shows a popup and also a valid database name after. Once a user opens the fingerprint to check the data, the code will execute but the dummy name will render on the Database Name field. This can be

Contact Details

1.01. Database Acronym

 Database Name Available.

1.02. Database Name

1.03. Institution name

Figure 3.7: Example of how an XSS attack could be done on MONTRA

EMIF CATALOGUE / European Network

Nothing selected

db

Fingerprint Documents

Hits: 5 Unique Views: 1 Filled: 1.7 %

CONTACT DETAILS

1.01. Database Acronym

1.02. Database Name

mednat.ieeta.pt:8624 says
 You were Hacked :/
 OK

Figure 3.8: Victim of a simple XSS attack

further exploited, where the user visiting the fingerprint will not notice that malicious code was executed.

All these problems exist because such views were developed from scratch without using the provided features that Django has out of the box for form validation and security. For client-side validation, Django takes advantage of HTML5 form validation features [37]. This allows imposing restrictions and validations on the user's input without writing any additional javascript code.

To show these features I wrote a simple HTML file with a simple form that expects a number under 100 and an email.

```
<html>
<body>
  <form>
    <label for="num">Number:</label>
    <input id="num" type="number" max="100">

    <label for="mail">Email:</label>
    <input id="mail" type="email">

    <button type="submit">Submit</button>
  </form>
```



Figure 3.9: Error messages that appear after submitting the form on a chromium based browser

```
</body>
</html>
```

If I try to submit the form with invalid values, error messages are presented as shown in figure 3.9.

Additionally, if the data is sent directly through an API call to the backend, Django forms framework ensures invalid data is rejected. With this, when building a form in Django the developer only needs to specify what fields are present and their type and restrictions and Django will validate all this before data is stored on the database.

Finally, XSS attacks are prevented because Django escapes the values that were previously provided by users when filling the input tags, e.g. the character “<” is transformed in “<”, avoiding the browser to interpret user’s input as HTML code.

Another problem associated with the views of the MONTRA framework is how the management of javascript dependencies is done. There is no consistency on how such dependencies are imported. Some are imported directly on the template through *script* tags making use of a Content Delivery Network (CDN), as others their entire source were added to the repository and are then referenced based on their location. The first approach has the advantage that an upgrade is simply changing the URL attribute of the *script* tag and also reduces bandwidth from the Django server handling the user requests. The second approach increases the overall size of the repository, and the upgrade process will lead to more changes on the repository. These processes, however, have the problem that easily unnecessary dependencies will still be present on the Django templates after being used on the application. Currently, there are tools such as Node Package Manager (NPM)² that help to manage these dependencies by defining, on a single file, the dependency and its version. This software will then download the dependency and subsequent dependencies.

API

It was mentioned several times that some checks are not enforced through the API. It will be detailed now what calls are performed by MONTRA’s fingerprint views.

Note that there are two different APIs available here. Fingerprint views use one specific set of API requests that return answers in HTML format, ready to present to the user, and others to send the user’s data. For a regular user to use, there are other set o API endpoints

²<https://www.npmjs.com/>

Figure 3.10: Each question set has its container. Here the current container is presented within the red rectangle. The other existing question sets are represented through the blue lines, which currently are hidden.

that are more human friendly, which is documented and has a How to Use page, however, an advanced user can see what requests are made on the fingerprint views through browser's console and perform the requests themselves.

First, we will go over the API used by the fingerprint views. But before showing the available endpoints, let's go over how the fingerprint views are organized and how they show only the questions of a certain question set at a time.

Let use figure 3.10 as example. According to the right side menu, there are six question sets and currently the question set "Contact Details" is being presented. In the middle of the page, we then see the content of the question set: questions, title, control buttons, and permissions. Note that there is a scroll bar so the question set contains more questions. Also the previous, next, cancel and save buttons are not tied to the question set. The other question sets are also present on the page, however, are hidden. Every question set has its container, so whenever the user clicks on the previous or next buttons or selects another question set on the question set side menu bar, the current question set container is hidden and the new is shown. For questionnaires with a high number of question sets, rendering all available question sets could not be necessary. For that, a question set is loaded only when accessed the first time and following accesses will not require a load.

The fingerprint view can be used for four different use cases:

- Create a new fingerprint: The questions are presented with clear and editable inputs
- Edit an existing fingerprint: All questions are editable but the previously answered questions are filled
- View the answers of a fingerprint: A read-only version of the fingerprint's answers
- Search for fingerprints: Same as creating a new fingerprint, however, no validations are performed on the user's input

For these use cases, the following endpoints are used:

- Create

```
GET [base url]/c/[community slug]/addqs/[fingerprint hash]/[questionnaire id]/[question set id]/
POST [base url]/c/[community slug]/addPost/[questionnaire id]/[question set id]/[save id]
```

- Edit

```
GET [base url]/editqs/[fingerprint hash]/[questionnaire id]/[question set id]/
POST [base url]/c/[community slug]/addPost/[questionnaire id]/[question set id]/[save id]
```

- View

```
GET [base url]/detailedqs/[fingerprint hash]/[questionnaire id]/[question set id]/
```

- Search

```
GET [base url]/c/[community slug]/searchqs/[questionnaire id]/[question set id]/
```

For both cases where new data is stored, besides the usual GET that is used to load the question set, there is also a POST request that saves the progress done to a specific question set. The data for these requests are gathered natively by javascript once each question set container contains a *form* tag englobing all the questions inputs. This way there is no need to iterate over the questions of a question set and append each response to the request's data. The *save id* field of the endpoints tells to which question set the data is related to, however, there is already a *question set* field which always has the value of 1, so one of these fields could be removed from the endpoint.

The GET request is then used to load the HTML to present the questions of a question set. Note that the returned data is just the HTML data to be placed on the respective question set container and not the whole fingerprint page.

Moving now to the set of API endpoints available to the users to both read and update answer data the following are available:

```
GET /api/fingerprints/[fingerprint hash]/answers/
GET /api/fingerprints/[fingerprint hash]/answers/[question slug]
PUT /api/fingerprints/[fingerprint hash]/answers/[question slug]
```

The first two GETs are used to retrieve answers data, which is returned as the JavaScript Object Notation (JSON) object presented next, the only difference being the first one returns an array of the mentioned object instead of just one.

```
{
  "question": "patients_count",
  "data": ""
}
```

With the PUT request, a fingerprint owner can update data of specific answers where a JSON object should be sent in the body of the request with the field “data”.

```
{
  "data": 10000
}
```

Existing two different types of endpoints to retrieve answers data makes sense since the returned format is returned in a way that is easier to handle data by the target entity that will consume that endpoint. If the fingerprint pages receive the data in HTML format they can just put the HTML in the determined container instead of having to build the entire container and insert the data on each input. Accordingly, if data is returned in a JSON format it can easily access the data and perform some data processing avoiding going transverse the HTML and retrieve the data from each input. However, having two different endpoints to update data doesn't make that much sense since current HyperText Transfer Protocol (HTTP) requests libraries offer an easy way to build a request in the required format as the one's browsers automatically build whenever a form is submitted.

Draft

We will also go over the API endpoints that the front end code uses to request to change the fingerprint state from draft to published. Associated with this feature, there are two endpoints available:

```
POST [base url]/api/pending/[fingerprint hash]
POST [base url]/api/draft/[fingerprint hash]
```

The existence of two endpoints for the same purpose is because Communities have a setting that allows to auto-accept requests to publish a fingerprint. For that, whenever the auto-accept setting is off, the first endpoint must be used, which will send a request to the community owners to publish the given fingerprint. The second must be used otherwise.

The problem with this approach is that the code that decides what endpoint to use is on the client-side and there is no server-side check if the correct endpoint is being used. If the auto-accept setting is off and the second endpoint is used, a user can publish his fingerprint without requiring the approval of the community owners.

3.1.4 Import Questionnaires - Excel

As mentioned before, to define a skeleton of the metadata that describes a data source for a given community, a spreadsheet file has to be submitted. There is already a template with some instructions and columns where a community manager only has to fill the necessary rows to then get the wanted result.

The column defined in the template are the following:

- Type: the type of the specific row. Here are allows 3 different values:
 - QuestionSet: allows dividing the questionnaire into several sections
 - Question: a question specification
 - Category: allows to create a group of questions inside a question set

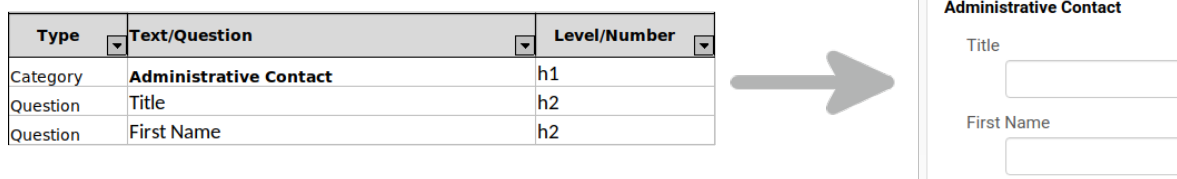


Figure 3.11: Create a group of questions with a title

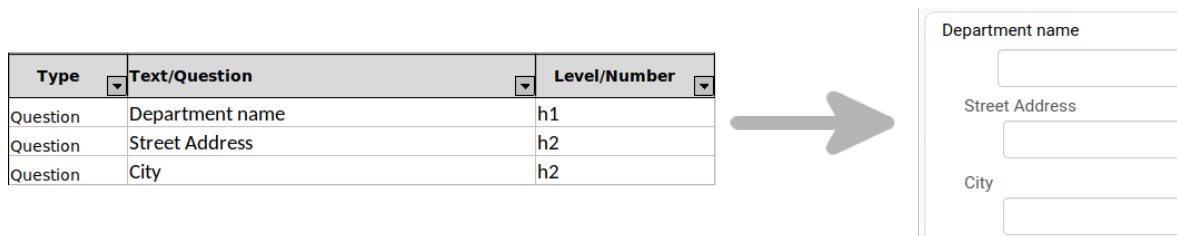


Figure 3.12: Create a group of questions using a question's text as the title

- Text/Question: label/name given to the item being defined
- Level/Number: use as a level for questions and categories and number otherwise. As level allows to create groups of questions inside a question set. As number defines the number, and subsequently the order, of the question sets.
- Data type: used only for rows of type Question, specifying the question type
- Value list: used to indicate extra information to build the question
- Help text/Description: a small text that will be displayed along with the item being defined
- Tooltip: Yes if the Help text/Description should be displayed as a tooltip or No otherwise
- Slug: internal identifier
- Dependencies: used to tell that a question or group of questions can only be answered if a specific choice of a choice-based question was selected
- Stats, Comments Stats and Disposition: Columns that were used for old features but are still present on the spreadsheet
- Include in Advanced Search: if the answers of the question can be used to search fingerprints

Question Groups

From the previous list, question groups were mentioned both when the type column has the Category value and on the Level part of the Level/Number column. The former is used to add a title with no question associated, resulting in what is presented in figure 3.11.

On the latter, the text of the question in the most upper level is used as the title of the questions group, resulting in an output similar to the one in figure 3.12.

It's important to highlight that the category way to create question groups is not independent of levels. If both a category row and a question are on the most upper level, MONTRA will render two separate collapsable containers, where the first one will be empty, as is shown in figure 3.13.

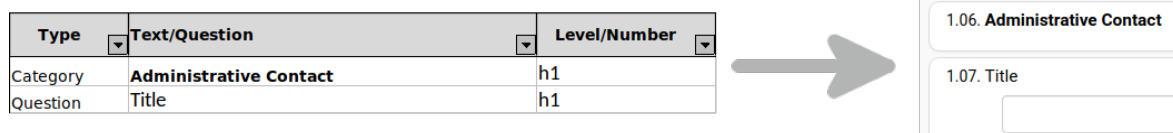


Figure 3.13: Example to show that the category way to create question groups also depends on the values that are set on the level column

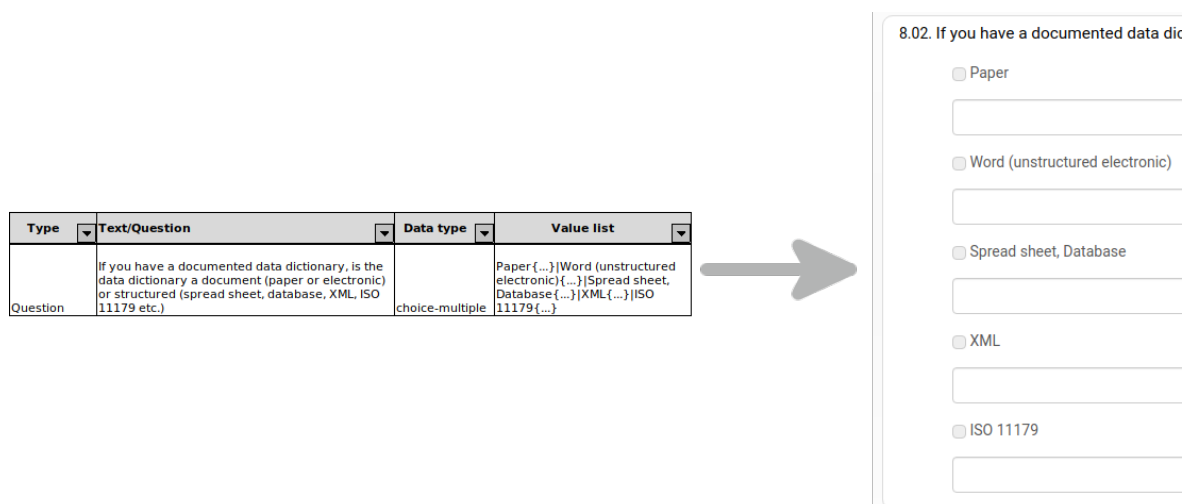


Figure 3.14: Multiple choice question with some extra text fields associated with the several choices

Value list

To avoid having a spreadsheet with several columns that will not be used for all types of rows, the value list column expects some extra information required for some types of questions.

Choices

For choice-based questions, the value list column is used to define the possible choices and to add an extra text field associated with a given choice. Choices are separated by a “|” character and the extra text field can be set by appending “{...}” after the target choice’s text.

Although the framework allows the extensibility to have an additional text field, these don’t support other types of input and also have no validation. Also, if the number of choices is high and the text of them is long, there starts to exist some clutter on the spreadsheet. With this, the person creating the spreadsheet will have problems perform edits and check if there is something wrong or missing.

To facilitate the job of who is filling the spreadsheet, some question types are shortcuts. For example, the choice-yesnodontknow is a question of type choice with three possible options: Yes, No, Don’t Know. Choice variants with freeform on the name, besides the usual choices, always have an additional text field, associated with the question instead of a choice.

Type	Text/Question	Data type	Value list
Question	Clinical test parameters results.	open-multiple-composition	{title:"Weight X", field:"msurex", editor:"input"}, {title:"Height", field:"msurey", editor:"input"}, {title:"Msure Z", field:"msurez", editor:"input"}

↓

12.08. Clinical test parameters results.

Please capture the results for the variables of the clinical test B.

Date	Weight X	Height	Msure Z
30/07/2021	10	10	

Figure 3.15: How an open-multiple-composition question type is specified on the spreadsheet and how it is rendered

Open Multiple Composition

Open multiple questions allow showing a history of a given value. For that the simple version of the question is represented in a table of two columns: Date and the value, so no input is expected on the value list column. The composition version of the question type allows having several values, instead of just one. In a way, the simpler version can be used as a shortcut question type, since it can be reproduced with the composition variant.

To render this question type, a third-party widget called Tabulator³ is being used. The configuration of such widget, expects an array of JSON objects, each specifying some configuration of each column. To configure the open multiple composition question type, the value list column expects these JSON objects, where the date column is implicit. The MONTRA framework will then put the provided objects on the configuration array that the Tabulator widgets expects, adding the configuration for the date column.

Choice Tabular

This type of question allows reusing the same choices across several answering items. There are three variations of this questions types, where the difference between them is what and how is the information connected between answering items and choices. There are two versions where the user can select one (single choice) or more (multiple-choice) choices for each answering item. The other version allows the user to write text for each choice within each

³<http://tabulator.info/>

Figure 3.18: The questions with dependencies are not rendered if the specific choice is not selected

Figure 3.19: Once the dependency of a specific question is met it will be rendered

figure 3.17, since a choice-yesnodontknow question type has three implicit choices, by having a dependency with the value “Any_blood_collected|1”, both the *Blood collection* category and the *Plasma* question will only be displayed to the user once the choice *Yes* of the *Any Blood Collection?* question is selected.

Besides such restrictions are imposed on the user when he visits the web page, if the API was used directly, such dependencies would not be checked, which would lead to unnecessary data be stored on the database since it won’t be displayed to the user.

3.1.5 Data Models

This section will be presented how the previous concepts are mapped to database models. Taking advantage of Django’s ORM feature, MONTRA’s data models are defined as python classes that extend Django’s base Model class. These Model classes belong to different applications, which are associated with distinct aspects of the platform.

In figure 3.20 is presented the class diagram of the classes that are related to features and/or concepts that were mentioned in previous sections. Classes with the same color belong to the same Django application, dividing them into specific purposes.

- Blue - Django’s built-in authentication system⁴.
- Orange - Fingerprint application: Answers to questionnaires questions and other models associated with features that were mentioned on the fingerprint views section, such as AnswerRequest and FingerprintSubscription. MONTRA also keeps a record of all the states of a given Fingerprint. For that, it uses the FingerprintHead model, which maps to a set of AnswerChanges.
- Purple - Questionnaire application: Questionnaires structure information such as question sets, questions, and choices, and import spreadsheets logs. Additionally, associated with each fingerprint, contains a model with the allowed permissions on each question set.

⁴<https://docs.djangoproject.com/en/1.11/ref/contrib/auth/>

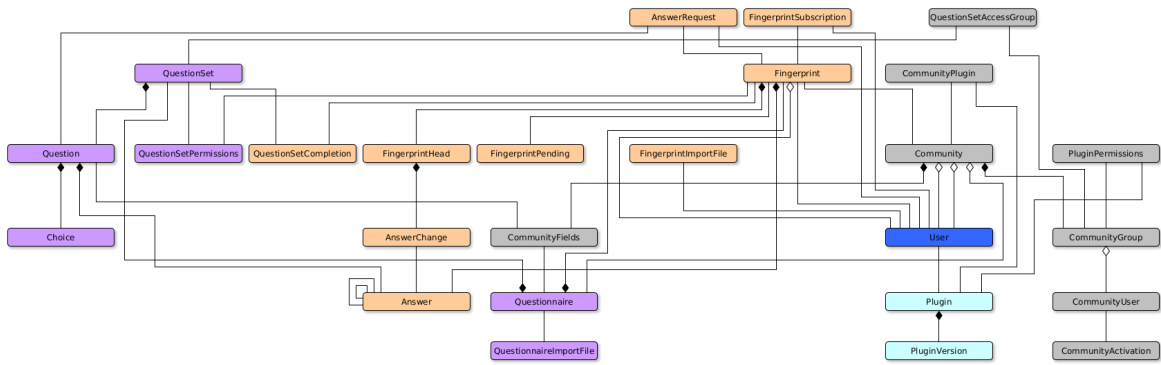


Figure 3.20: Class diagram of MONTRA's Model classes. Each color has a Django application associated. Gray: Community; Purple: Questionnaire; Orange: Fingerprint; Light Blue: Plugin; Blue: Django Auth. MONTRA's data model is much more complex, however, it is just presented the ones that impact the features and/or concepts mentioned previously.

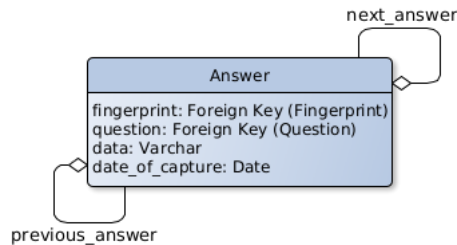


Figure 3.21: Detailed information of the Answer model of the Fingerprint application

- Light Blue - Developer application: Allows adding customizations to different MONTRA's installations through plugins.
- Gray - Community application: Community's groups, users and access permissions, fields to be presented on the fingerprint list page for each questionnaire and plugins.

Going into more detail on some models we can see some poor design decisions.

Regarding fingerprint answers to a questionnaire, all the data is stored in the Answer model on the data field, which is a variable-length string field type. Although this approach is much simpler in terms of data models, it leads to two problems:

1. this is not the most optimized way to store all the data types. Some question types expect numeric values and other date values, which could use built-in field types of a relational BDMS.
2. for complex question types which the answer contains several fields, before and after storing such data in the database, some processing has to be made to convert the data to the necessary format. One example of this is multiple choice questions, where the value of the several selected choice is joined in a single string to then be stored on the database. Every time the answer needs to be displayed to a user, it is necessary to split that string by its separator. For this situation instead of storing the choice's value, the models of the questionnaire application could be used as a foreign key.

Related to MONTRA itself, when a user provides no data to a specific question, an empty string will still be sent for that question on the submission of the answers to a question set,

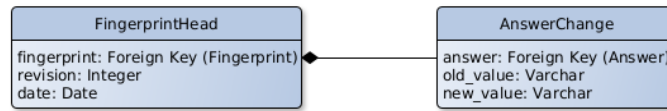


Figure 3.22: Models that store the changes to answers of fingerprint

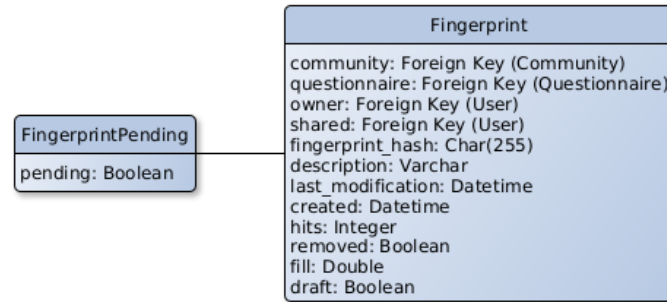


Figure 3.23: The Model that stores the information telling if a fingerprint is waiting to be approved to be published

which will create unnecessary records on the database.

As mentioned previously, MONTRA records the history of submissions for a specific fingerprint. Each submission has an associated FingerprintHead record, which its name might have been inspired by the HEAD concept of Git⁵, a version control system. For every FingerprintHead there is a set of answers that suffer changes which are then recorded on the AnswerChange model. In this model, we can get the answers data duplicated three times since it is already stored on the Answer model and can also be stored again as text in both *old_value* and *new_value*.

As mentioned previously, a fingerprint is not immediately available to all regular users, since it first enters on a draft state. To transit to the published state, a request needs to be made to the community owner. Such requests are stored on the FingerprintPending table, where the pending value will be *true*. Once a request is rejected or accepted, the value of the pending value is changed to *false*.

On the Fingerprint model, there is also a *draft* value that indicates if the fingerprint is published or not. Once a fingerprint is published, the value of the *draft* will be *true*, and on the FingerprintPending table, the associated record will have the pending value at *false*. However, this value is not required to be stored on the database since after a fingerprint is published, the fingerprint will not be pending therefore, the associated FingerprintPending record could be deleted.

Whenever a questionnaire is imported, a QuestionnaireImportFile record is created containing the information of the uploaded file and the user that uploaded it. Also contains a status field to give some feedback to the user. Associated with every import will also be created a Questionnaire record. It contains an *in_preview* variable that is set to *true* whenever a questionnaire is in the import process. If it fails to import, only the QuestionnaireImportFile

⁵<https://git-scm.com/>

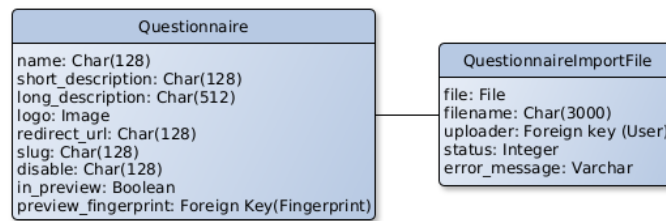


Figure 3.24: Questionnaire model and the model where questionnaire imports information is stored

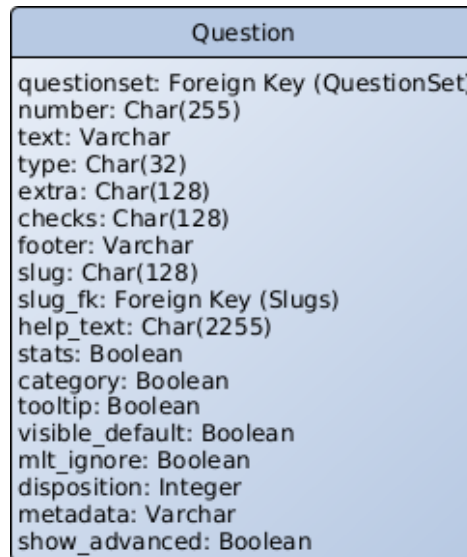


Figure 3.25: Question model and its extensive number of fields

record will be kept, which the status will change to *Failed* and an error message will also be attached to the import record.

If the questionnaire is valid, the user will be redirected to a page where he can preview the result and can accept or reject it. It is important to point out that for the preview process a new Fingerprint object is created so API calls can be performed.

Strangely on the Questionnaire model, the disable column uses a character type column instead of a boolean one since it expects only the value of “False” and “True”. If there are some user input errors, it could lead to unexpected behavior or internal server error.

Associated with how the structure of a questionnaire is stored, there are only four models to do so: Questionnaire, QuestionSet, Question, and Choice. All are associated with a specific concept of the questionnaire, although other concepts are not represented. First, there’s the category, used to create question groups within a question set. It is represented as with a question record, where the “category” field of the question models has the value “true”. For more complex question types that require extra configuration such as choice tabular, which requires information about the name of the rows and column, and open multiple, which expects the configuration of the columns, such data is stored in a metadata field of the associated question model. Question types that do not make use of these fields, will have an empty value, leading to some database space being wasted.

When the questionnaire’s spreadsheet was explained, some fields were related to some old deprecated features. The question model contains the same fields that map to the questionnaire’s spreadsheet deprecated fields: `stats`, `visible_default`, and `disposition`. There is also a `slug_fk` field that points to a Slugs model that replicates the question’s slug and text, which is was used to yet another deprecated feature.

Finally, a question supports for the user to define additional checks which are defined on the “checks” field however, this feature is not exposed through the questionnaire’s spreadsheet.

3.2 REFACTORING

Until now it was shown how the MONTRA framework was designed around databases, their metadata, and how that metadata can be shared among the platform users. For regular users the framework provides a good user experience, however, for power users, that make use of APIs, might make some errors which the framework will not prevent, leading to inaccurate data to be stored and presented. Also for developers, such flaws and bad design choices make the maintainability process of MONTRA instance a demanding and tedious process.

With this, there is a clear opportunity to perform a refactoring process over the framework to correct such problems and the issues that have been emphasized in this chapter. The goal of this refactoring process is not to change the framework in a way to transform existing use cases, but to improve its internal structure to make the framework more stable, easier to maintain, and easier for an external tool to communicate with it, mainly to publish database data.

Next, we will propose several changes to be applied to the framework, beginning from the data models, regarding how fingerprint answers data is stored, how questionnaires structure is stored and some other fixes for some defects explained previously. Such refactoring will imply changes on other components, one of them being the rendering of questionnaires and how input validation is done. Finally, several clutter problems were mentioned when describing the spreadsheet to define a questionnaire structure, so the spreadsheet will also undergo a refactor.

3.2.1 Data Models

Since the MONTRA framework uses some outdated software and there are active installations, the refactoring process can not be simply designing new models and views, implementing them, and replacing old ones is not a viable option. The approach taken was to first decide what components would go through a refactoring process and within each, until what level we would apply it.

Taking into account figure 3.20, since both the Community and Developer (Plugins) Django applications target functionalities not so fingerprint-centric and are more related to features of the framework as a whole, we decided not to perform any changes on the models of these applications. This leaves us with both the Fingerprint and Questionnaire applications. Regarding the Fingerprint application, the fingerprint model is one of the main models of the framework, affecting several features of the framework, so we intend to perform minimal

with the NULL value.

Moving now to the models related to the Questionnaire application, there is a new Question model mainly because the previous one had too many fields. An example of these extra fields is the *metadata*, which is used to store the information of the column of the open-multiple question type and the choices and answering items of a choice tabular question type. This field was replaced by the addition of new models (Label) which will be explained in more detail in the next Excel subsection. Another example was the category field, which indicated if a specific question record described a category in the questionnaire which was being used to create subgroups of questions. With the new models, a new Group model was created which has a set of questions associated. Previously this relationship did not exist, so MONTRA would create a group based only on the question's order and level. Additionally, with the addition of this Group model, there is no need to have a level field on the question type, since nested levels are represented through Groups, which can have a parent group. A group with no parent is represented in the root level of the questionnaire. The remaining models (Label, Choice, and their descendants) will be explained in more depth in the next Excel subsection since they were created mainly because of how questions are represented in the new spreadsheet format.

Meanwhile, there are previously existing models that have undergone changes to fix some design flaws mentioned before.

- QuestionnaireImportFile: To provide feedback to the user this model only contained an *error_message* field. However several times there are some errors with the questionnaire, but the framework can continue. In these situations, a warning could be sent to the user just so he is aware that a part of the spreadsheet has some errors and the result could not be his real end goal. Then the new model contains two new fields, *errors*, replacing the old *error_message*, and *warnings* fields, which are stored in JSON, where the keys are the lines where the errors or warnings were found and the values are an array of messages associated with that line.
- Questionnaire: associated with the questionnaire model we mentioned that it had a specific fingerprint attached that was used to show a preview of the result of the questionnaire. This field is not required since the preview mode of a questionnaire is viewed on read-only, so no answers are associated with these preview fingerprints.
- QuestionSetPermissions: From this model, we removed the useless permission of "Allow Printing", considering it is impossible to restrict users from printing the page since a screen capture software can be used as a replacement for the browser's print function. Also, there was a record associated with each question set of every fingerprint, even if the values of each permission were the default ones. The new approach taken is to only create a record if any permission value is different from the default one. Otherwise, an object with the default values is returned.
- Fingerprint: It has a new "submission_token" used for the new API endpoints explained next.

3.2.2 Views

When the MONTRA framework was presented it was highlighted that the different variations of the fingerprint view (create, show, edit, search, preview) were all using a different Django template. Once again, this brings the problem that one change will entail that the same change has to be applied on the remaining fingerprint view variations. On the refactoring process, these views were adapted so all the different pages use a shared fingerprint template which then renders the necessary components according to the page where are being rendered.

The first step of this process is to put different components into separate templates, which will then allow the creation of different arrangements of such components according to the fingerprint view variation being displayed. Note that even within these new separate components, some parts of them might be rendered differently according to the fingerprint view variation where they are being inserted into. In figures 3.3 and 3.4 we can see that some components are present on both views. The question set title, the questions, the question set menu, the fill progress bar, and the navigation buttons. However, we can also see some components in figure 3.4 which are not present on the on figure 3.3 such as the fingerprint statistics (hits, unique views and fill percentage), there are no fingerprint-related buttons, which are now questionnaire-wide buttons. Note that the name of the fingerprint (DemoAveiro), the several tabs (Fingerprint, Documents, ...), and the subscribe and Manage buttons are specific to the show Page. The new fingerprint template will only contain components to display within the Fingerprint tab.

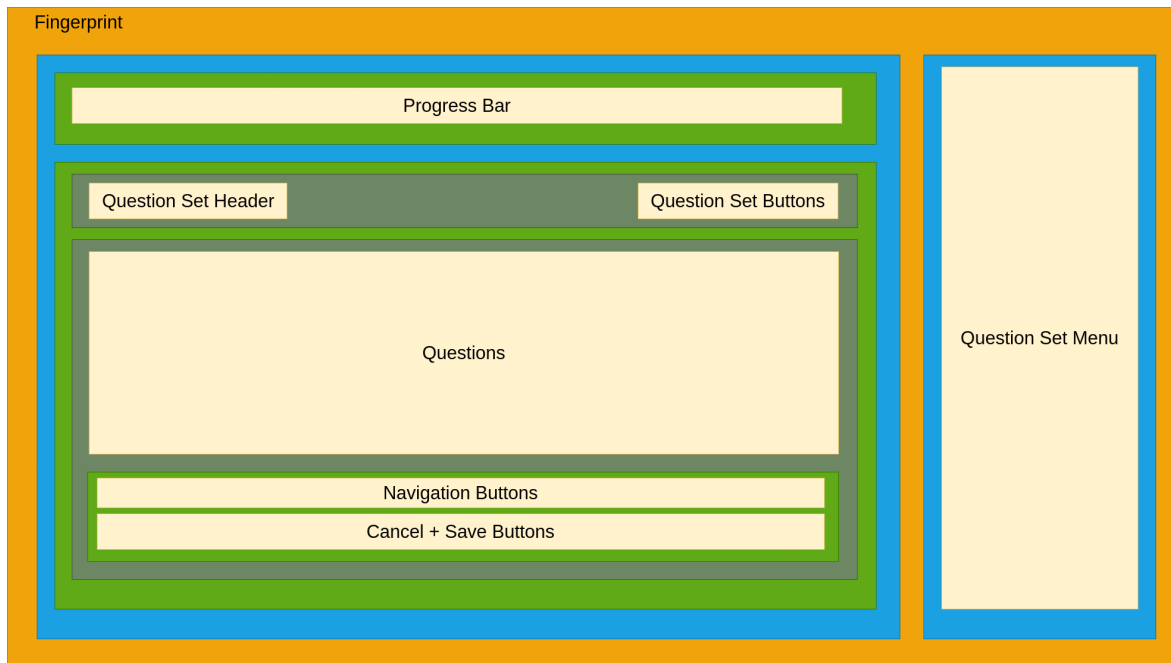


Figure 3.27: New fingerprint template for the create, edit, search and preview fingerprint views variations.

In Figure 3.27 is presented a two-column layout for the create, edit, search and preview variations of the fingerprint view. Although, some components are not displayed in certain

variations, such as the Cancel and Save buttons. The Cancel button is not displayed on the preview variation, and both Cancel and Save buttons are replaced by a Search button on the search button. Additionally, different buttons appear on the question set buttons component according to the fingerprint view variation.

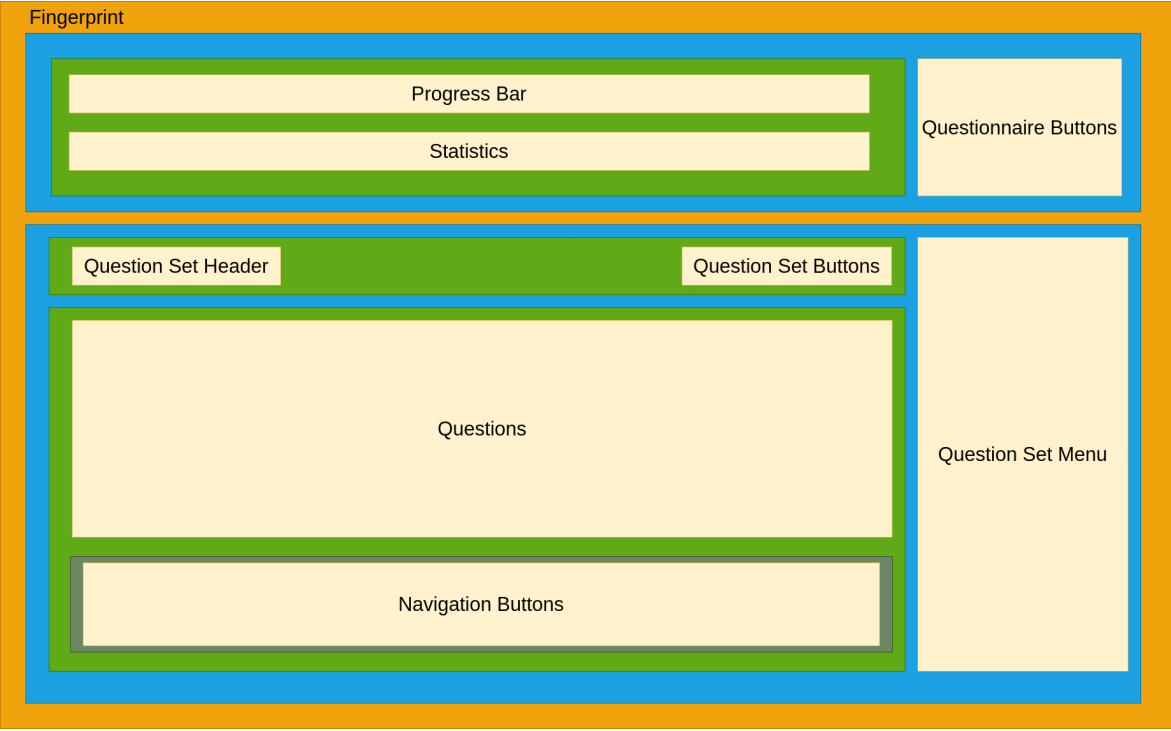


Figure 3.28: New fingerprint template layout for the detailed show fingerprint view variation

The show variation, as shown in figure 3.28, uses a single column with two rows layout. Previously the show variant had no Question set buttons, however, to keep consistency with the other variants, the Collapse and Show buttons were moved to the Question Set Buttons where they were being displayed on the other variants. By default, the only button visible on the Questionnaire buttons is the Summary, which will hide the current detailed view and show an alternative summary layout, where answers are displayed in several tables, one for each question set.

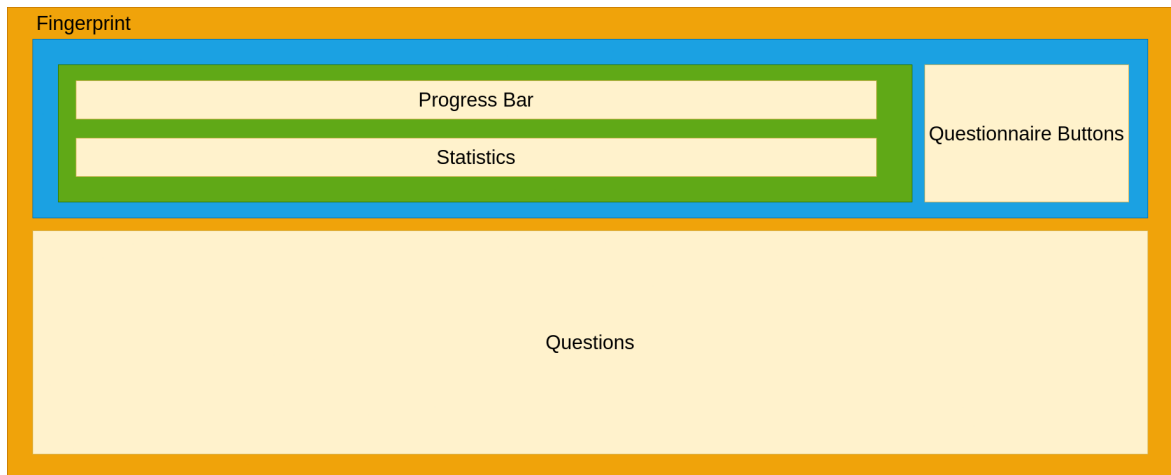


Figure 3.29: New fingerprint template layout for the summary show fingerprint view variation

As can be observed in figure 3.29, when the user switches to the summary view, by clicking on the Summary Questionnaire button, the detailed view container is hidden, and the summary view container is displayed.

It's important to note again that the overall aesthetics and workflow of the page were not changed. The only major change was to divide the fingerprint view into several, reusable components.

When we went over how question sets were rendered, we saw that each question set had its container and they are only rendered when is accessed for the first time. When it needs to be rendered, API endpoints are used to fetch the HTML of a specific question set. On this HTML returned, each question had attached their client-side validation code. The goal is to remove all existing code of client-side validation, making use of only simple built-in HTML validations on the client-side and use Django's forms framework to have all remaining validations on the server-side.

Before going into more details let's go over Django's built-in form system and some of its components. A form in HTML is represented through the form tag and fields are represented through input tags. Each input tag has a type attribute that defines how the data will be inserted by the users, for example, to insert a date the user will be presented with a calendar where it can click on the desired date. These different ways to insert data are called widgets. To work with forms, Django only makes use of two HTTP request methods: GET and POST. GET is used by browsers to fetch the page/HTML of an URL and it can also be used to fetch information. POST on the other side is used to send information to a server. On the backend side, Django has three main classes that handle the data around forms. The main one is the *Form* class that defines how it works and how it will be presented to the user. Then there is the *Field* class that describes a field of a form, which is in charge of performing field-specific validations. Django already has some implementations of this class for the most common field types such as number, text, choice, ... Finally, the *Widget* class is in charge of processing and transforming the raw data received and also preparing and restructure data to be presented to the user, and again Django already has some implementations of this class. Each *Field*

class has a widget class associated. The common development flow is to create a child class of Django's *Form* class and then define its fields with *Field* classes.

However, in the case of MONTRA, the number and type of the fields are dynamic, since both can be customizable by a community manager when he is building a questionnaire. A Submission form was created, child of Django's *Form* class, where its constructor was overridden so the fields of the requested Question Set of a Questionnaire are defined in the form class. Additionally, several question types lead to the need of having to create and associate new *Field* and *Widget* child classes since they were too complex to be represented or validated with the ones that Django already has implemented. To build the widgets of such question types, existing implementations were ported to an associated Django template to then be used in its new widget class.

By removing all validations from the front end, client-side code is now only used to make API calls to the backend, to validate the data inserted by the user, and to add functionality to the page itself, such as hide and/or show elements on the page after a button is clicked. All client-side code related to the fingerprint was either migrated or newly implemented using, as much as possible, plain javascript, avoiding any external library. It avoids adding yet another dependency to the project, and if in the future, upgrades are done to libraries such as JQuery⁶, the code implemented here is not affected and does not require any refactoring.

3.2.3 API

As all the validations were moved to the backend, it was necessary to create several API endpoints that perform them. Such validations take advantage of Django's form system, so in the implementation of each endpoint, it is only necessary to build a SubmissionForm then add the data provided by the user and then call its validation method, which will validate all the fields that were defined in the form.

Besides the user input validation, there need to be new endpoints that render the HTML of a question set of a questionnaire using the new questions models and Django's forms system. As different fingerprint view variations might present the questions and answers differently, there are different endpoints for each fingerprint variant:

```
GET [base url]/questions/[questionnaire id]/[section index]/preview/
GET [base url]/questions/[community slug]/[questionnaire id]/[section index]/search/
GET [base url]/questions/[community slug]/[questionnaire id]/[section index]/create/
GET [base url]/questions/[questionnaire id]/[section index]/create/

GET [base url]/questions/[fingerprint hash]/[section index]edit/
GET [base url]/questions/[fingerprint hash]/[section index]/show/
```

There are two different endpoints for the create variant, because certain installations are a single community, for that, the community is implicit, but for multi-community installations, the community slug is required, since the same questionnaire can be used on different communities.

⁶<https://jquery.com/>

For the edit and create variants, there need to be additional endpoints that are in charge of performing all the validations associated with each field and saving the progress when the user changes from one question set to another if no error is found. Bellow are such:

Submissions Management:

POST [base url]/api/submission/save/[community slug]/[questionnaire id]/[section index]/

POST [base url]/api/submission/save/[questionnaire id]/[section index]/

PUT [base url]/api/submission/save/[fingerprint hash]/[section index]/

Questionnaire Information:

GET [base url]/api/questionnaire/info/[community slug]/[questionnaire id]/[section index]/

GET [base url]/api/questionnaire/info/[questionnaire id]/[section index]/

Related to the Submissions Management endpoints, which are used to save answers data, the first two endpoints follow the same idea as the ones presented before, which on single community installations there is no need to provide the community slug. However, there is a third alternative. The first two should be used when there is not yet a fingerprint created, and which will return both the fingerprint hash of the created fingerprint and the current submission token. The fingerprint hash is the identifier of a fingerprint, the submission token is used to identify if different calls to the save endpoints are related to the same changes. With that, several changes can be grouped in the same Submission, instead of the previous implementation that would create a FingerprintHead record for each save of a question set.

This also enforces that if the user performs several changes to the same question set with the same submission token, only the last changes will be kept, replacing (figure 3.30), or even deleting (figure 3.31), old answer values sent in the same submission.

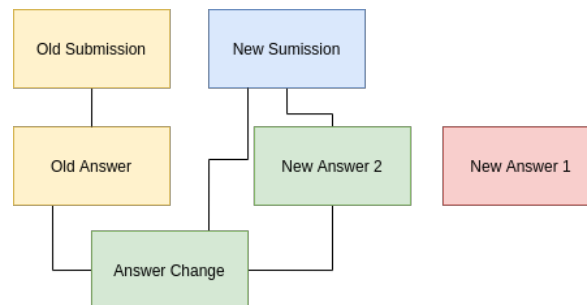


Figure 3.30: When an answer change is submitted and there were already changes made to that question, then the previous one is deleted (New Answer 1) and a new one (New Answer 2) is associated with both the current Submission and the related Answer Change.



Figure 3.31: If the user either provides an empty value or no value to an answer that previously had a value on the current submission, associated Answer and Answer Change records are deleted.

If no submission token or one that does not match the current one is provided, then it is assumed that the changes submitted are related to a new submission, thus the most recent submission is closed and the new provided answers are added to a new submission.

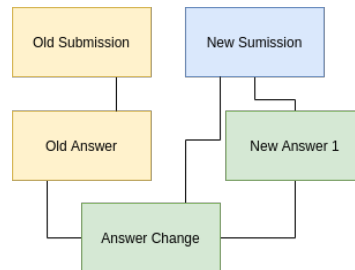


Figure 3.32: Whenever new changes to the answer of a question in a specific submission are submitted, a new Answer model is created, and also an Answer Change record is created connecting with the previous answer. In the case the provided submission token does not match the current one stored in the fingerprint model, then a Submission record will also be created, and changes will be associated with this new Submission.

Previously it was possible to update an answer of a single question through endpoint `/api/fingerprints/[fingerprint hash]/answers/[question slug]/`, mentioned in the API portion of section 3.1.3, which was a more user-oriented alternative to the ones that were used on the old fingerprints views. On the new endpoints to validate and save the answers of a question set, if a single answer is sent, Django’s form system will consider the rest of the answers to the other questions of the question set as empty. With this, the user is forced to always send the previous answers to all other questions plus the updated answer of the specific question. To avoid this, the `/api/fingerprints/[fingerprint hash]/answers/[question slug]/` endpoints were kept, refactoring them to use the new models and Django’s form system, but in these, the form used to perform the validation only contains one question instead of all questions of a question set.

With all this changes to the endpoints, choice-based answers are stored as a foreign key to the choice(s) selected. This implies that the answer’s data sent on the Submissions Management endpoints for such question types must be these foreign keys, avoiding misspellings and non-existing choices. However, one does not know the keys for each choice and also the available choice if the web view is not used. For that, the Questionnaire Information endpoints are used to get information of choice-based questions, so that the correct data is sent along with the Submissions Management endpoints.

Draft

There were also some modifications to the endpoints to change the publish status of a fingerprint. Instead of having two different endpoints for different community settings (to auto-accept or not fingerprint publish requests), but for the same purpose, now only one exists.

POST `[base url]/api/draft/[fingerprint hash]`

This endpoint expects the same data in the same format, though takes different actions according to the community of the fingerprint at issue. Also, on the previous versions of publishing endpoints, there was a possibility to publish fingerprints that weren't complete, not having answers to required answers. Now, a validation is implemented when the user wants to publish its fingerprint, not completing the change on the publish status if the fingerprint is not complete. This avoids notifications being sent to the community manager telling that a user wants to publish a fingerprint, although such fingerprints might be incomplete.

3.2.4 Excel

The previously presented version of the spreadsheet used to define a questionnaire, had some problems in terms of clutter due to the overuse of the “Value list” column to define the extra configuration of specific questions types. The column was used to define all choices and their extra information of choice-based questions, to define columns and their settings of open multiple question and columns, rows, and type of choice tabular questions.

To fix those clutter problems, improvements were done to the spreadsheet by deleting some useless columns that were related to deprecated features and adding new types of rows that define the extra configurations for those questions types that require.

Starting by the columns of the actual spreadsheet now are the following:

- Type
- Text/Question
- Data Type
- Help Text/Description
- Slug
- Dependencies
- Constraints
- Tooltip
- Include in Advanced Search

Most of the columns are already known from the previous version, “Constraints” being the only one that was added to this new version. The columns that were removed are Stats, Comments Stats, Disposition (all associated with deprecated features), Level/Number (the number is now automatically retrieved according to the order of how the rows are defined), and Value List (brought the clutter problem to the table).

Type

On this column, the only possible values available were QuestionSet, Question, and Category. The new version has now eleven possible types of rows for the spreadsheet:

Type	Text/Question	Data type	Value list
Question	Clinical test parameters results.	open-multiple-composition	{title:"Weight X", field:"msurex", editor:"input"}, {title:"Height", field:"msurey", editor:"input"}, {title:"Msure Z", field:"msurez", editor:"input"}



Type	Text/Question	Data type
Question	Clinical test parameters results.	open multiple
Column	Weight X	short text
Column	Height	short text
Column	Msure Z	short text

Figure 3.34: Differences between how a open multiple question was versus how is now defined on the questionnaire spreadsheet.

Type	Text/Question	Data type	Value list
Question	Does this take place in participants' homes or at a central location?	choice-multiple-freeform	Home{...} Central{...}



Type	Text/Question	Data type
Question	Does this take place in participants' homes or at a central location?	multiple choice
Choice	Home	
ChoiceInfo		short text
Choice	Central	
ChoiceInfo		short text

Figure 3.35: Differences between how a open multiple question was versus how is now defined on the questionnaire spreadsheet. Note that now it is possible to specify the data type of the extra information that is attached to the extra information of a choice.

of that group to a deeper level with no group label. This however would make the spreadsheet even longer for certain questionnaires that make use of categories to group questions that have some dependency on another question. Figure 3.36 shows how the change would affect the spreadsheet.

Type	Text/Question	Level/Number
Category	Treatments	h1
Question	Relapse Therapy	h2
Question	What is the requirement of this data?	h3
Question	Number of registrations	h3
Category	Disease Modifying Treatments (DMTs)	h2
Question	Past disease modifying therapies	h3
Question	What is the requirement of this data?	h4
Question	Number of registrations	h4
Question	Start and end dates of past treatments	h4
Question	What is the requirement of this data?	h4
Question	Number of registrations	h4
Question	Current disease modifying therapies	h3
Question	What is the requirement of this data?	h4
Question	Number of registrations	h4
Question	Start date of current treatment	h4
Question	What is the requirement of this data?	h4
Question	Number of registrations	h4
Question	Reasons for discontinuation of DMTs	h3



Type	Text/Question
Group	Treatments
Question	Relapse Therapy
Group	
Question	What is the requirement of this data?
Question	Number of registrations
EndGroup	
Group	Disease Modifying Treatments (DMTs)
Question	Past disease modifying therapies
Group	
Question	What is the requirement of this data?
Question	Number of registrations
Question	Start and end dates of past treatments
Question	What is the requirement of this data?
Question	Number of registrations
EndGroup	
Question	Current disease modifying therapies
Group	
Question	What is the requirement of this data?
Question	Number of registrations
Question	Start date of current treatment
Question	What is the requirement of this data?

Figure 3.36: A possible solution to avoid relying on the Level column to create subgroups of questions. On the new solution proposed it's much difficult to know at which level the specific question is located, without looking at the rows above.

Even with colors, the user editing has to look several rows above to know at each level it

is so he can match the “EndGroud” rows with the respective “Group” rows. This is the same problem as matching if open and closing brackets on C-like programming languages. Such a problem is alleviated since indentation is allowed, which can’t be achieved on a spreadsheet. For those reasons, the Level column was kept, however, when a questionnaire is imported, whenever there are nested levels the framework will create groups with empty text.

Data Type

As it was possible to see in figures 3.33, 3.34 and 3.35, the Data Type column is used to detail the type of data that will be stored and how it will be requested to the user in terms of HTML widgets.

Table 3.1 contains all the previously allowed question types, a total of twenty-five different types. On the new version, this list was reduced, where some questions can now be achieved using simple question types in conjunction with the new row types that extend their base functionality.

Next is the list of question types available after the refactoring:

- short text: Old open. It replaces the open-validated field by making use of the new Constraints column;
- long text: Old open-textfield
- single choice: Used to achieved any old single-choice question type. The extra information input can now be achieved with the ChoiceInfo row type;
- multiple choice: Used to achieved any old multiple-choice question type. The extra information input can now be achieved with the ChoiceInfo row type;
- integer: Old integer;
- date: Old datepicker;
- email: Old email;
- url: Old url;
- numeric: Old numeric;
- publication: Old publication;
- image: Old open-upload-image;
- choice tabular: Old choice-tabular;
- open multiple: Can achieve both the old open-multiple and open-multiple composition

Open-location and timeperiod were removed since they weren’t being used on any of the active installations of the MONTRA framework. The same happened with sameas and custom as additionally, they were shortcut type questions.

Slug and Dependencies

Previously the dependencies between questions were detailed by providing the id of the target question and the order of the choice that was needed to be selected, but since now the choices are described by row, the user can also detail an id for them, which such id can then be used on the Dependencies column of the questions that depend on such choice.

Constraints

The old Question model allowed to add custom checks, however, this feature was not possible to make use of through the spreadsheet, it was only possible to define them after the questionnaire was imported. This “Constraints” column intends to enable configuring such additional checks. Checks were previously stored in a custom format, where each check was separated by a space, defined as *name = "value"*. To avoid having to parse a string every time we want to load the constraints, they are now stored in a JSON field. Regarding the spreadsheet, the format chosen was a modified version of the original checks, supporting several types instead of interpreting every value as a string, allowing flexibility on the whitespace between each and within a check. Next is presented some examples:

```
name: "value"  -> string
name: true    -> boolean
name: 1       -> integer
name: 1.5     -> numeric
name: value2  -> also a string
```

JSON was also considered, however it was too much verbose to put on a spreadsheet cell, emerging the clutter problem.

Currently, the supported constraints are the following:

Question Type(s)	Constraint
any	required
short text long text	min_length
	max_length
	regex
integer numeric	min_value
	max_value
date	min_date
	max_date
	format

Table 3.3: Newly available constraints to apply to a question

3.3 SUMMARY

In this chapter, a metadata storing and visualization tool, the MONTRA framework, was detailed and analyzed, highlighting some of its poor design choices, which impact its usability and maintainability. A refactoring process was performed to fix such problems, preventing and giving feedback on user error when submitting data and improving the overall maintainability of components related to the metadata displaying.

The next chapter will go over the remaining part of the process regarding metadata. Extracting it from a database and then send it to update tools that store and display it, such as an installation of the MONTRA framework.

Automatic Metadata Extraction and Update

As we have an application ready to receive and display metadata, it is now crucial to turn the attention to extracting metadata from CDM databases, which contain the actual data, allowing, then, to update the data stored on applications such as the MONTRA framework.

Figure 4.1 presents a high-level architecture of the desired system that extracts data from databases and sends it to the applications that need their local data updated. Agents are software that runs on the data owner's deployment, in charge of extracting metadata from the database and sending this metadata to the applications.

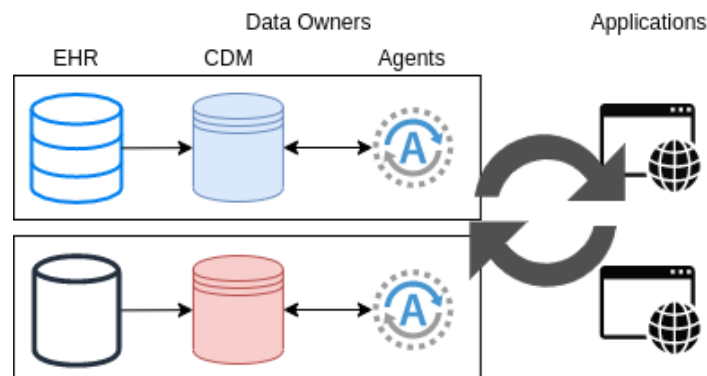


Figure 4.1: High-level architecture of the extraction and update process.

4.1 REQUIREMENT ANALYSIS

When we enter the realm of accessing an institution's sensitive data, some problems start to arise. Not all data owners are willing to, or legally can't, provide direct access to their data. When building this part of the system, we have to consider this and have several options available that use different levels of access and according to the demands of each specific data owner, use the most appropriate one. In one end, a single solution could have full access to

the data, extracting the metadata directly from the original data. At the other end of the scale, the burden of extracting data is removed from us and the system is dependent on the data owner providing the metadata and only then the system processes the metadata. Having several options for different access levels is more flexible, however, it requires maintaining several tools which are not reliable. A more appropriate alternative is to have a single option, that is designed considering the most strict access to the data, however, we still need to provide a tool to extract the metadata. The only difference is that we are not the ones executing it.

As the extracting tool has direct access to the data, using an existing and widely known tool is a must, so data owners are inclined to use it. Additionally, making fewer to no changes is preferable to ensure that data owners don't discard the tool because they don't trust the changes.

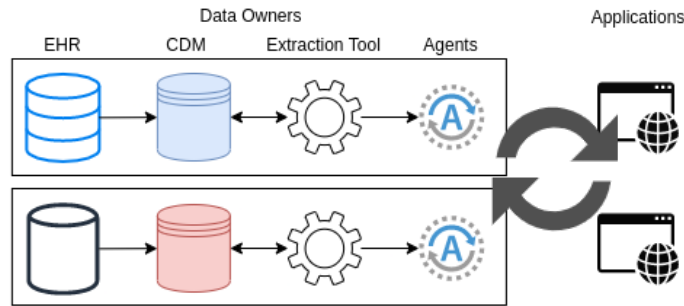


Figure 4.2: High-level architecture of the extraction and update process

In figure 4.2 is presented the overall architecture of the system, where the agent is the tool in charge of parsing the metadata provided by the data owner, which is then sent to the applications. Regarding this last point, there needs to be a way for the data to go from the agents to the applications. One ambitious solution is to create a decentralized peer-to-peer network of agents, avoiding developing a central component. In such solution, the agents are in charge of managing and sending the data to the applications. However, data owners might not want to spend their hardware resources to maintain a network. Since the agents are executed on the data owner's system, they should do only the required and minimal functionality, spending the few resources as possible.

A more executable solution is to have an intermediate component that receives the metadata from the agents and then distributes that data across the applications, following a centralized network architecture as it is presented in figure 4.2.

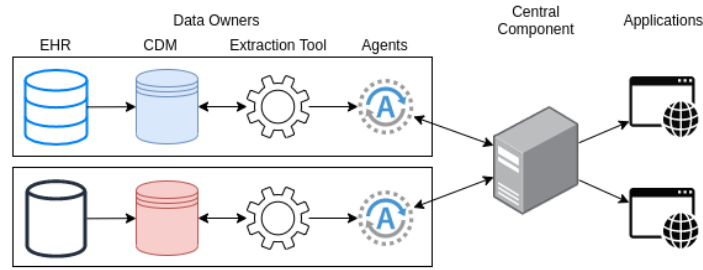


Figure 4.3: High-level architecture of the extraction and update process, with a centralized network approach.

This central component will be used to manage the data and the applications to where such has to be sent. However, it is also crucial that feedback is provided on the system's state, such as how the data is flowing, which applications received which data, and which databases sent data into the system.

On the applications side, there are other important factors to consider before going forward on implementing the intermediary component mentioned before. First, then we talk of application we are considering only web application that expect to receive metadata through a Representational State Transfer (REST) API. Second, the APIs of different applications expect the metadata in distinct arrangements. A way out of this would be to specify a set of endpoints that each application had to implement, yet that would lead the applications to have two sets of endpoints that do the same thing. On the other side, making a flexible option, where the requests where the data is sent are customizable, would be more appealing for the target applications, which would not have to make any changes. Third, not all applications require all metadata data that is extracted from a database. Some use all the data, others only need a value of such data.

4.1.1 Functional Requirements

1. Databases must be registered on the central component
By having a record of the databases that are attached to the network, the system can avoid accepting data from databases that were not registered in the system.
2. It must be possible to check what agents are active at a certain point
This allows giving feedback on the state of the network to the admin.
3. The system should allow managing the destination applications
The applications to where the data of the databases are sent, should not be hard-coded, for that, the network admin should be able to perform CRUD operations on such. The term application should be interpreted as web applications that have REST API endpoints available to receive data.
4. The system should provide statistics on the data that has circulated
This is yet another feature to give feedback to the network admin about, now allowing to both check the amount of data that each database sent, and the amount of data that each application received.
5. The format of the request sent with the metadata to each application must be customizable

This is important since different applications expect to receive metadata in distinct formats since each application has a different API.

6. The system should allow to group Databases

In a scenario where both all the destination applications and all databases belong to the same project, the metadata of the databases makes sense in all applications. Now consider a scenario where half of the databases are associated with one project and the rest with another. Each project has a destination application that receives the data. Considering that there is no concept of project or groups, both applications will receive data of both projects. To solve this, it required to have two installations of this system, one for each project. By grouping databases, data of a database can be guided to applications that are also attached to the same group.

4.1.2 Non-Functional Requirements

1. The data owner can stop the agent at any time

This gives yet another layer of control to the data owners over their data. If at any time, they don't want to share their data, they can stop the agent. This also poses a constraint in the system that it should not be designed assuming that the agents, once deployed, will always stay active.

2. The extraction tool should be based as much as possible on an already existing solution

Using a working solution avoids having to build a new tool from scratch. But apart from that, using a known solution as a base helps to gain the confidence of the data owners so that they use the resulting solution in their databases.

3. The agents must not have direct access to the data

This option assumes the least amount of access to the user's data so data owners are receptive to allow agents to be run on their local deployments. This will require that an agent has access to at least a shared storage where agents check for new data and data owners post their extracted metadata.

4. The agent should easily deployable

As the installation of the agent will be done by a person not familiar with the project, this process should be as smooth as possible and well documented.

5. Agents should spend few resources

Considering agents run on data owners' deployment environment, it should have a low resource footprint so it does not impose any disruption. For that, they must be designed to perform only the required task.

6. The system should not require any open ports on the data owners' deployment environment

As there might be communication between the central component and the agents, requesting an open port on the data owners' deployment environment might not be possible since it could require them to change firewall settings as was mentioned in [31].

7. Scalable

As more databases are connected to the network, the system should allow increasing resources so that it handles processes faster.

8. Microservice architecture

The system should be composed of simple and replaceable components that deal with well-defined tasks.

4.1.3 Use Cases

From the previous requirements defined, there can be outlined two actors that will interact with the system:

- Data owners, which maintain the agent on their local deployment;
- System admin, that interacts with the central component to manage the whole system.

In figure 4.4 is presented the use-case diagram, which shows the actions that each actor performs on the system. Such actions were divided into three groups: Agents, Metadata Extraction, actions on the central component related to receiving data from the agents, and Metadata Update, actions on the central component related to sending data to the applications.

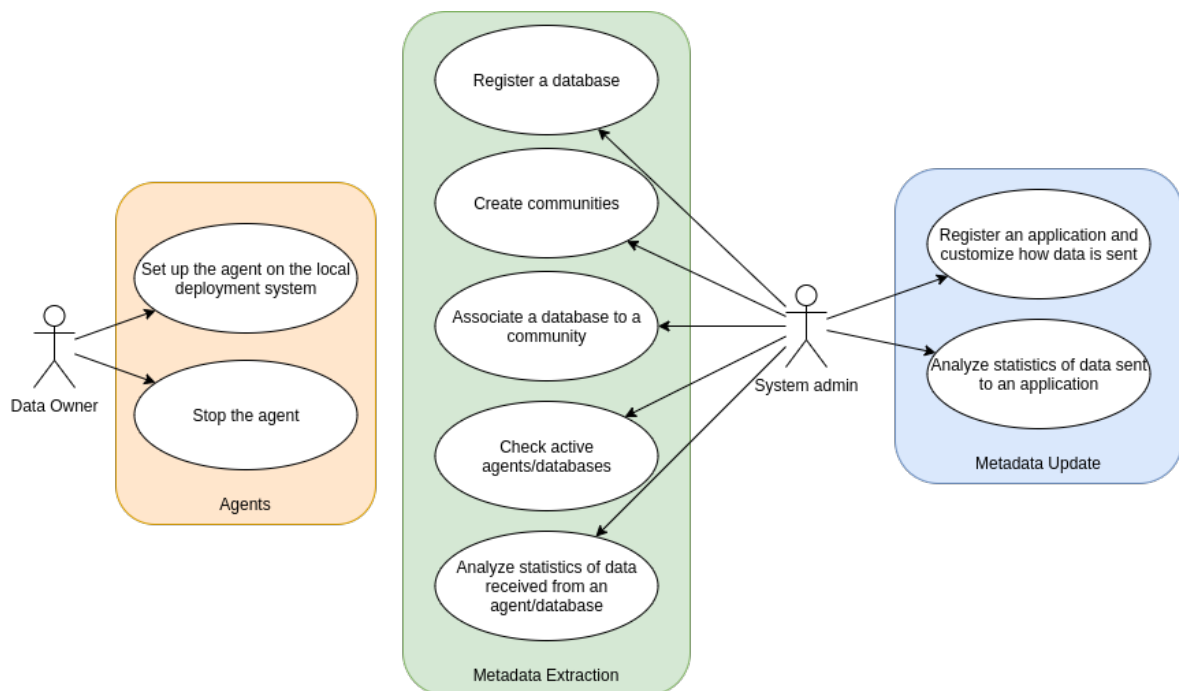


Figure 4.4: Use case diagram of the metadata extraction and update system

1. Set up the agent on the local deployment system

Since it's not expected that data owners provide access to their deployment environment, the responsibility to set up the agent is imposed on them.

2. Stop the agent

As Data owners control their data and the access to it at all times, them stopping the agent should be an action expected by the system.

3. Register a database

As new databases enter the network and agents are deployed to gather their metadata, the system admin needs to register new databases on the central unit, so the data received is accepted into the system.

4. Create communities

In a scenario where there are several databases from distinct projects, there is the need to group databases to treat their data separately.

5. Associate a database to a community

Once there are databases and communities registered in the system, the system admin can do many-to-many associations between them.

6. Check active agents/databases

At any time, the system admin can check the state of the network and verify which databases have an agent active.

7. Analyze statistics of data received from an agent/database

As agents send data to the central component of the network, statistics can allow the system admin to see what databases contribute more data to the network and its frequency.

8. Register an application and customize how data is sent

The system admin will also define the destination applications for the data received from the agents, setting also the format of the request that sends the data to such applications.

9. Analyze statistics of data sent to an application

As metadata enters the system, having statistics of data sent to the application helps check if the system is working properly and if the applications are receiving the expected data.

4.2 EXTRACTION

With the requirements analysis done, let's first go over the portion of the system which executes in data owners' space.

4.2.1 ACHILLES

Regarding the extracting tool, from the ones presented in chapter 2, the most indicated for our use case is ACHILLES, developed by OHDSI, or a variations of such. This choice was mainly because of its database, instead of dataset, focused design and because it is built to extract metadata from databases that follow the OMOP CDM.

Catalogue Export [26] was built using ACHILLES as base, the main difference being that exports only the required data from OMOP CDM databases which is used on the EHDEN project.

These tools are distributed as an R¹ package, which uses a set of third-party packages that allow to extract metadata from different Relational Database Management System (RDBMS)s.

¹<https://www.r-project.org/>

Metadata is separated into analyses, where each one captures a specific metadata metric of the database. Each analysis is captured through a different SQL query, allowing to extract all analyses following a multithreading approach. To make use of the package, the user must provide the information to connect to the database, such as user and password, an output directory to export the results and the name of three schemas, which are, in most RDBMSs, a way to group tables within a database within the RDBMS. The schemas to provide are:

- CDM Data: where the original CDM data is stored;
- Results: that contains the tables that store the results obtained from the execution of analyses queries;
- Vocabularies: as each clinical database certainly will contain their distinct internal representation of clinical concepts, such as a database might encode sex with just a character (f, m, o) others might encode with the whole word (female, male, other), the OMOP CDM makes use of standardized vocabularies that allow to create an homogeneous representation for different databases. Such vocabularies can be acquired on the OHDSI's ATHENA website².

As this R package should only perform reads on the original data, it is preferable that the package uses a custom user that only has read permission on the cdm data schema. This can also be applied to the vocabularies schemas, as the package will use it only to perform joins with the CDM data. Regarding the results schema, read and write permissions are required to insert the results data of the analyses queries.

The package also allows to export the results data to a Comma-separated values (CSV) file, which, on the EHDEN project, is then uploaded into a plugin of EHDEN Portal [6], which was built using the MONTRA framework, the main topic of the previous chapter, called Network Dashboards [38]. This plugin makes use of the metadata from the resulting file of the Catalogue Export tool to build several dashboards with charts (figure 4.5) that allow for researchers to better analyse and compare the data of clinical databases.

²<https://athena.ohdsi.org/>

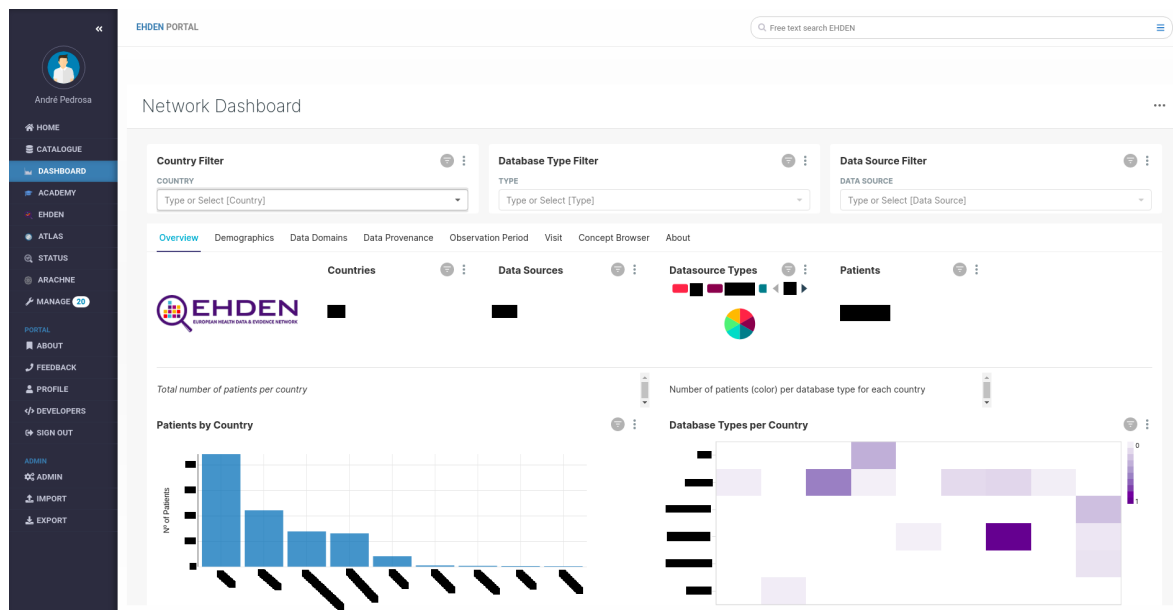


Figure 4.5: Network Dashboards plugin used as a plugin on the EHDEN Portal

4.2.2 Asynchronous Message Systems

isto é preciso para haver comunicação entre agents e a central unit

RabbitMQ

Kafka

4.2.3 Kafka Source Connectors

- fetch from files or from tables
- falar nas varias opcoes consideradas. as the tables não davam tudo duma vez, e as alternativas de ficheiros não davam feedback de quando tudo já tinha sido uploaded
- o que eu escolhi da feedback de quando todos os records estão kafka e quantos records foram escritos

4.2.4 agent final architecture

1. data owners should automatize (if they want) the process of extracting data from their databases
2. send data to kafka
3. responde to health check messages
4. automação da extração está nas mãos do data owner mas existem ferramentas simples como o crontab que executam comandos a determinadas horas

4.3 PUBLISHING

data is in kafka. what do we have to do to reach the applications idealmente usamos o kafka e afins para tudo, não tendo de desenvolver nada

- need to send custom data on a CUSTOM FORMAT to a custom REST endpoint

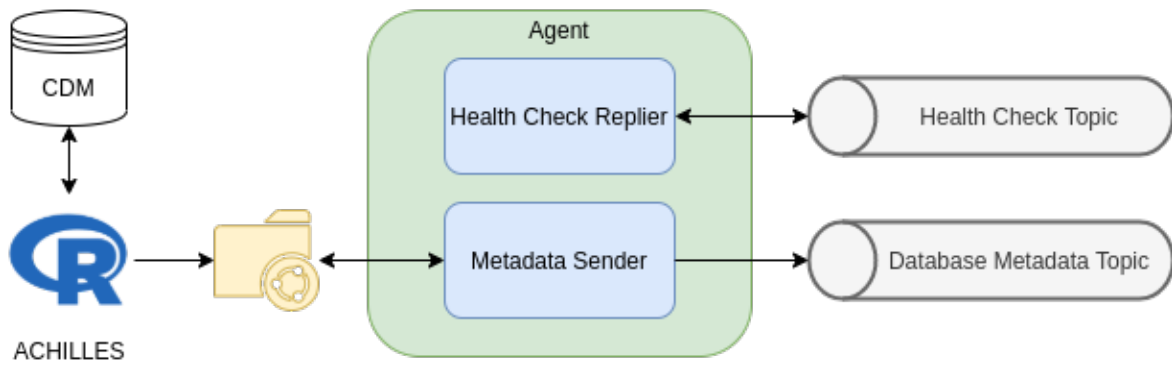


Figure 4.6: agent arch

- Kafka Sink Connectors (The target REST API is not customizable, such as the data format) - need for a sender application
- No known end on kafka topics/streams - require some management on top of kafka

4.4 NETWORK MANAGER

- centralized entity
- transforms the data to the required format
- sends to the specific application's endpoint
- 5 components

4.4.1 Pipelines Workers

- lets do it in go cause lets explore
- search for kafka library
- ksql introduced. easily filter data with select __ where __
- select and filter the data coming from the databases
- only process data of a single database at a time. handling multiple is the same is hard to handle and hard to scale
- scalable: several pipeline worker applications

4.4.2 Orchestrator

- To ensure multiple records of multiple databases are not processes at the same time, this component redirects the data from databases to the pipelines workers preventing the previous problem
- why java? (only it contains a kstream api) and we use it to redirect messages from one topic to another

4.4.3 Sender

- sends/publishes the data resulting from the pipelines, to the application's endpoints
- why python? cause jinja and pandas (people know how to use)

4.4.4 Admin Dashboard

- search for technologies (first golang pls . <https://github.com/qor/admin>)
- 2 components: api backend (django) + react frontend
- manage the whole thing
- Allows to perform all the use cases

4.4.5 Statistics Recorder

- Listens to the kafka topics that are used along the system and transforms into persistent data (sql)

4.5 NETWORK DATA FLOW

- Evaluation?
- step by step
- number of topics involved

CHAPTER 5

Evaluation

CHAPTER 6

Conclusion

future work - criar um mecanismo de chaves por comunidade. quando uma bases de dados envia dados sabemos imediatamente a que comunidade pertence - usar a autenticação do kafka para validar os dados recebidos das bases de dados - criar um mecanismo de teste para as pipelines e subscrições

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