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Adaptability of Existing Feasibility Tools for Clinical Study Research Data Platforms

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Abstract. Introduction The increasing need for secondary use of clinical study data requires FAIR infrastructures, i.e. provide findable, accessible, interoperable and reusable data. It is crucial for data scientists to assess the number and distribution of cohorts that meet complex combinations of criteria defined by the research question. This so-called feasibility test is increasingly offered as a self-service, where scientists can filter the available data according to specific parameters. Early feasibility tools have been developed for biosamples or image collections. They are of high interest for clinical study platforms that federate multiple studies and data types, but they pose specific requirements on the integration of data sources and data protection. **Methods** Mandatory and desired requirements for such tools were acquired from two user groups — primary users and staff managing a platform's transfer office. Open Source feasibility tools were sought by different literature search strategies and evaluated on their adaptability to the requirements. **Results** We identified seven feasibility tools that we evaluated based on six mandatory properties. **Discussion** We determined five feasibility tools to be most promising candidates for adaption to a clinical study research data platform, the Clinical Communication Platform, the German Portal for Medical Research Data, the Feasibility Explorer, Medical Controlling, and the Sample Locator.

Keywords. FAIR, data reuse, findability, data provision, software tools, user interface, feasibility, clinical study

1. Introduction

Innovations in artificial intelligence typically require large amounts of data of appropriate quality. In biomedical research, clinical studies - including cohort studies - constitute one of the best-curated data sources with comprehensive quality control. In the recent years, especially during the SARS-CoV-2 pandemic, the interest in infrastructures and technologies for the exchange and analysis of data from clinical

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research and healthcare has increased notably. Since 2017, the FAIR guiding principles for research data stewardship, i.e. findability, availability, interoperability and reusability of data, aim to ensure the necessary data provision and data quality for reuse [1]. In biomedical research, employment of existing data, in particular deeply phenotyped cohorts, offer an important source for generating knowledge about complex interactions between health and several internal and external factors [2, 3].

If a researcher wants to answer a scientific question by reusing data, it is important to consider the availability of the envisioned data items and subjects. Feasibility tools, where researchers browse and filter through the data sets support this. Openly accessible examples for such tools are the UK Biobank Showcase [4], the Sample Locator of the German Biobank node [5] and the Feasibility Explorer (FE) of the German Centre for Cardiovascular Research (DZHK) [6]. In case all data and information for the particular research project are (presumably) available, the researcher may decide to file an application to the data provider.

In contrast to data providers that are responsible for a single study, clinical study research data platforms such as the DZHK Heartbank [7] and the Clinical Epidemiology and Study Platform of the German Network University Medicine NUKLEUS [2] maintain multiple studies, that share common data sets, harmonized study and consent documents. Furthermore, image and biospecimen management systems are hosted at different locations. This poses a mandatory requirement that the feasibility tool needs to dynamically query data from different data sources. This feature facilitates also compliance with the European General Data Protection Regulation (GDPR), as only data required to answer a specific feasibility request needs to be transferred. This architectural prerequisite is only one of various requirements. Publicly available translational research platforms were analyzed and evaluated using the categories: community, information content, privacy management environment, analysis support, interoperability support, system requirements and platform support [8]. Ten requirements along five categories have been identified specifically for feasibility tools, given in Table 1 [6].

Table 1. Identified requirements for a feasibility explorer grouped by category [6]

Category	Requirement
Development	• Version control • Collaborative work of multiple developers
Privacy	• Re-identification of participants must not be possible • Raw data must not be available to the end user
Visualization	• Meaningful representation of the collective without enabling in-depth analyses • Dynamic visualization according to the selected filters • No technical requirements on the client side
Dynamic expandability	• Automatic filter generation according to the underlying data in order to use the application for different data sets
Integration into the application process	• Save filter settings • Transfer filter settings to the application process

Lablans et al. [9] described challenges, requirements and proposed solutions for translational cancer research networks, like requirements for semantic and technical interoperability, record linkage, pseudonymization and data sovereignty. In addition to functional requirement surveys for such tools, a user-friendliness study has been conducted on three tools. Besides the usability tests, the study also included an evaluation of the correctness of the content of search queries [10].

The aim of this paper is to assess existing solutions for feasibility tools and evaluate them regarding the adaptability for a multi-study research data platform. A mandatory requirement is that the tool is open source, as we see a continuous demand on adaption to new data sources, interoperability standards, user interfaces and regulatory requirements. Such a flexibility and individual configuration demands are typically not affordable in commercially licensed tools. Furthermore, as publicly funded research infrastructure, open science and transparency are considered good scientific practice.

2. Methods

2.1. Requirement analysis

A requirement analysis was performed via structured interviews with non-technical users that perform feasibility queries (primary users n=5) and persons that are involved in the technical development of a transfer office including a feasibility tool (secondary users n=4). A questionnaire was used to elicit requirements from both groups by means of open and closed questions. Three open questions were asked:

- What are the most important three criteria that such a tool must be able to do?
- What are the technical requirements?
- What are technical requirements in terms of data protection?

These questions served to collect the individual positions of the respondents at the beginning and to uncover new aspects.

This was followed by an evaluation of already collected requirements for a transfer office software [11], as such a tool differs mainly in the target group and an extended functional scope: The transfer office tool is used to find matching data sets, which equals a feasibility request. However, it includes also mechanisms to compile and anonymize the dataset. These requirements encompass 23 closed questions, which the users on a Likert scale from one (must be implemented) to six (must not be implemented) evaluated. We would like to emphasize, that both ends of the scale are highly relevant, with six as an exclusion criterion. All 23 questions related to four main topics: (1) feasibility request, (2) feasibility response, (3) general, and (4) graphical user interface (GUI). We summarize the results of the requirement ratings.

2.2. Search strategy and selection of feasibility tools

We performed a multilateral search, employing known publications, expert knowledge and PubMed. Among our search results, we included all tools, which offer the function to make a request or query, have a filtering option or to select data based on a specific research question. It should also provide clinical data as well as biomedical data or biospecimens. We excluded analysis tools, clinical trial tools, imaging tools, literature search engines, metadata repositories, reference manager, screening tools, statistical software or statistical packages and tools with another focus. We started from already known publications, following hints by the community and experts, and searched for similar articles via keywords provided in publications found. In case of multiple publications on the same tool matching our search, we selected the one with the most implementation details. A total of 18 publications were found. Three tools including a

metadata repository and two study hubs, were excluded. We excluded feasibility tools such as TriNetX [12], if they are not open source. We then combined the key words found in these articles, and performed a literature search in PubMed. All used words are given in the following simplified search-string:

(OR(feasib*, request*, query, queries, response*, filter*, search*, retrieval, data sharing, data analysis, data analyses, distributed analys*, exploration*, data handling, data integration*, patient selection, visualisation*, visualization*)) AND (OR("Information storage and retrieval"[Mesh], tool*, software*, system*, portal*, platform*, dashboard*, explorer, locator*, user interface*, GUI, data repositor*, database*, registry, registries, research infrastructure*, warehouse*)) AND (OR(trial*, study, studies, medical, research, clinical, data, patient, subject, electronic record*, health record*)) AND (OR(biomedical, biomedical data, biospecimen*, biological specimen*, bio sample*, biosample*, biological sample*, sample data)).

In total, we found 80 articles (without duplicates), where 76 abstracts were available. 26 were excluded due to unavailability of fulltext, 39 were excluded based on manual abstract inspection. From the remaining 11 publications, 19 tools extracted, three of which excluded due to a different focus, namely repository exploration, screening of participants for clinical studies and a biomedical search engine. Thus, the literature search screening resulted in 16 tools, with an overlap of seven tools that were also found through community leads.

Finally, 24 tools remained for further review, which were evaluated by requirements that were found most relevant through the analysis (sect. 2.1).

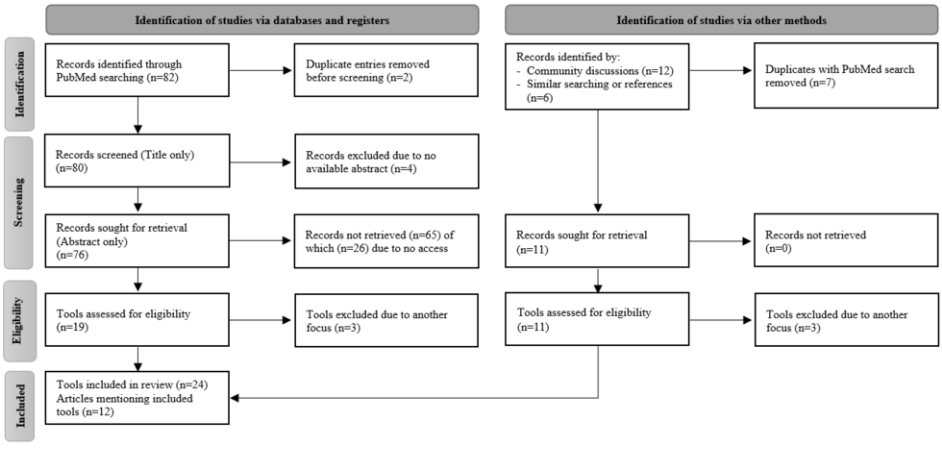

Figure 1. Flow diagram of the selection process for feasibility tools (based on [13]).

The flow diagram according to the Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA) guidelines for structured reviews [13] is shown in Figure 1. The search was completed between January and May 2023.

2.3. Selection of features for the evaluation

A mandatory requirement is that the tool is open source. Therefore, we consider in the evaluation only tools that currently fulfill this requirement.

Based on the requirement analysis we added six mandatory criteria to evaluate the selected tools.

3. Results

3.1. Requirement collection

Table 2 describes the key attributes to a feasibility tool that we collected from the open interview questions.

Table 2. Answer to the open questions - categorized by the main topics introduced in 2.1. p.u. = primary users, s.u. = secondary users

No.	Requirement	Category	
	What are the most important three criteria that such a tool must be able to do?		
O1	feasibility criteria quarriable, complex quarriable, handle all possible queries, selection by collective, mappable with everything/extensible	feas. req.	p.u.
O2	easy to use, self-explanatory, help tool (chat bot), intuitive interface design, tool guide, customizability, compatibility	GUI	
O3	filter options, accuracy of content	feas. req.	s.u.
O4	user tests for forms, the use of AND/OR, data dictionary	general	
O5	feedback on data availability, exportable or responsive data, store and managed applications, link to exports and data sharing, completeness of data, all data from all systems, accuracy of content	feas. resp.	
O6	easy to use - self-speaking user interface, provide common standard environment, study documentation,	GUI	
	What are the technical requirements?		
O7	export pseudonyms can be created, if possible all data	feas.resp.	p.u.
O8	no feedback of data to patients, correctness of data, definition of data, access restriction	general	
O9	show cancellation of request, filter info e.g. in JSON, filtering/cross-linking of data, request data via interfaces	feas. req.	s.u.
O10	roles/rights distribution, monitoring of access, immediate consideration of consents, AND/OR linkage - completeness of data, speed of data request	general	
O11	if possible all data	feas. resp.	
O12	open overview	GUI	
	What are technical requirements in terms of data protection?		
O13	containment of the patient, extra pseudonyms (custom), possible tracability of data and match the biospecimens, data protection according to GDPR, anonymized + pseudonymized data, no re-identification, no traceability to studies	general	p.u.
O14	basic aspects of data security, no central DB, data storage not on a server in the internet, no re-identification, no caching of data, data protection according to GDPR	general	s.u.

Regarding the most important features, both user groups mentioned that there must be a filter option (n=8/9) that can also implement complex queries. Primary users added the possibility to filter by cohorts/studies. Secondary users mentioned the feature to return the number of available data sets and, ideally, statistics (e.g. distributions across age, diagnosis, etc.). The option to export and store inquiries made by researchers, was additionally disclosed. Usability of the interface is mentioned as main non-functional feature (n=7/9).

The most important technical requirements related to data protection, are role-based authentication and authorization. This has been in particular mentioned by secondary users (n=2/4). In this context, access monitoring was also pointed out as an important requirement. Both user groups explicitly noted compliance with GDPR. Re-identification must not be possible, not even through any analysis methods (n=5/9). On the other hand, queries on all data items are desired (n=9/9). Federated search, to avoid central storage of data, was stated (n=3/4).

Table 3 shows that different requirements appear to be important between the two user groups.

Table 3. Most important requirements. n(m): n = rating, m = number of users that selected respective rating.

No.	Requirement	Evaluation		Category	
R1	The software must offer users the possibility of availability requests to the base systems.	1(3); 2(1)		feas. req.	Secondary users (4)
R2	The software must offer users the possibility to send availability requests with filter parameters.	1(3); 2(1)		feas. req.	
R3	The software may not store pseudonyms of the base systems in connection with the applications.	1(4)	M2	feas. resp.	
R4	The software must not save any data of the Trusted Third Party.	1(3); na(1)		feas. resp.	
R5	The software must comply with the data protection concept.	1(4)	M2	general	
R6	The software must work in the spirit of data economy.	1(3); na(1)		general	
R7	The software must filter the availability requests correctly.	1(4)	M3	general	
R8	The software must offer users the possibility to send availability requests with filter parameters.	1(4); 2(1)	M4	feas. req.	Primary users (5)
R9	The software must offer users the possibility to verify the consent of the study participants.	6(4); 1(1)		feas. req.	
R10	The software must be connected to the basic systems.	1(5)	M5	general	
R11	The software must comply with the data protection concept.	1(5)	M2	general	
R12	The software must filter the availability requests correctly.	1(5)	M3	general	
R13	The interface of the software should be clear, structured.	1(4); 2(1)	M6	GUI	

We find R2/R8 as well as R7/12 being identical and requested by both groups. In the primary group of users, feature (R9) "The software must offer users the possibility to verify the consent of the study participants" should not be implemented by the software due to data protection.

The mandatory requirements for evaluation of the tools were elicited, based on the most matches: (M1) open source (initial requirement); (M2) data protection summarizing the requirements R3/R5/R11; (M3) send requests with filter parameters; (M4) filter requests correctly; (M5) software connected to basic systems/federated search and (M6) clear and structured interface.

3.2. Identified feasibility tools

24 feasibility tools were found. The "Georgetown Database of Cancer (G-DOC)" [14] tool and the "Cancer Translational Research Informatics Platform (caTRIP)" [14] were removed from further investigation because they turned out not to be open source, after deeper investigation. No openly available source code could also be found for the "Electronic Health Records Systems for Clinical Research (EHR4CR)" project [15]. The tools "cBioPortal" [14], "Biology-Related Information Storage Kit (BRISK)" [14], "COVID-19 Exchange Data Platform (CODEX)" [16], "integrated clinical omics database (iCOD)" [14], "integrating data for analysis, anonymization and sharing (iDASH)" [14], "Informatics for Integrating Biology and the Bedside (i2b2) Query & Analysis Tool" [16, 17], "Medical-Blocks" [18], "tranSMART" [6, 16] and "Medex" [19] are central research data platforms or platforms built around a single database. Although in principle possible to adopt, we consider the effort required to customize them to be very high and have therefore not included them in the further evaluation. The "DEDUCE Guided Query Tool" [20] also follows "integrated rather than a federated" approaches, i.e. the data is gathered in a central data warehouse. The "Leipzig Health Atlas (LHA)" [21] consists of an i2b2 and a seek instance, that also rely on imported central data. In addition, tools with a different focus were not investigated further, i.e. the tool "Oncology Data Retrieval Systems (OncDRS)" [14] with a focus on genomic data and "DataSHIELD" [22] which is a multi-purpose tool for distributed computing. Finally the "COVID-Curated and the Open aNalysis aNd rEsearCh platform (CO-CONNECT)" [23] was excluded as the project terminated in October 2022 and there is no indication for further provision or development. The remaining tools are "OHDSI's ATLAS" [16], the "Clinical Communication Platform (CCP)" [24], the "Research health data portal (FDPG)" [16], the "DZHK Feasibility Explorer (FE)" [6], "MedCo" [25], the "Sample Locator" [16, 26] and the "Shared Health Research Informatics (SHRINE)" Network [27].

3.3. Evaluation of tools

Of all six features for evaluation of the selected feasibility tools, M1, M3 and M5 are inherently fulfilled due to the selection process. From the remaining three mandatory features, data protection is the most supported. Only SHRINE has been excluded here, based on the in-depth description from the developers of MedCo: SHRINE provides an ad-hoc mechanism for obfuscating query results and for locking-out investigators after a certain number of queries, whereas MedCo features a mechanism that achieves differential privacy [25].

Table 4. Selection of suitable tools in relation to the mandatory requirements in chapter 2.3.

Software/Tool	(M2) data protection	(M4) filter correctly	(M6) clear interface
ATLAS [10, 16]	YES [28]	**NO [10]**	**NO [16]**
CCP [24]	YES [24]	N/A	N/A
FDPG [16]	YES [16]	N/A	YES [16]
FE [6]	YES [6])	N/A	N/A
MedCo[25]	YES [25]	N/A	YES [25]
Sample Locator [16, 26]	YES	YES [10]	YES [10, 26]
SHRINE [27]	**NO [25]**	N/A	N/A

According to a comparative usability study, it turned out that ATLAS has a poor usability score for feasibility tests, as it has been designed as an expert tool [16]. M4 is rarely assessed in the literature and not assessable without knowledge about the ground truth, i.e. the underlying dataset. The only validation statement was found for the Sample Locator in contrast to erroneous results of the ATLAS tool [10].

4. Discussion

We have identified five feasibility tools to be the most promising for adoption to clinical study platforms. The tools provide different additional features. The (i) CCP tool provides a cohort dashboard, while the (ii) FDPG have connected result to an application process tool (ProSkive) [29], the (iii) FE provides the option to add the search as a code to the application, and the (iv) Sample Locator is combined with a tool to ask questions about details a researcher could not find with the tool. MedCo (v) ensures privacy-aware exploration of the data while being an extension of i2b2. All these functionalities have been mentioned as important during the user interviews. We conclude that no tool has yet covered the entire process from data query to data provision, but all tools are in principle eligible. Regarding sustainability [30] and compatibility, development on a common code base within the different biomedical research data infrastructures can help to build a development community that is large enough for long-term support and maintenance, in particular for security updates. As the CCP, Sample Locator and FDPG are closely related by their main developers, it might be advantageous to build on one of these tools. Furthermore, it might ease the development of meta-registries that will gain relevance with the envisioned data provision governance within the European Health Data Space.

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Conflicts of Interest: All authors declare no potential conflict of interest.

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