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Development of an Interactive Dashboard for OSSE Rare Disease Registries

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Abstract. Background: The Open Source Registry System for Rare Diseases (OSSE), a web-based tool to create rare disease patient registries, currently offers no possibility to view aggregated registry data within the system. Here, we present the development and implementation of a dashboard for the registry of the German NEOCYST (Network for early onset cystic kidney diseases) consortium. Methods: Based on user requirements from NEOCYST, we developed a general dashboard for all OSSE registries, which was extended with NEOCYST-specific statistics. Results: The dashboard now allows users to gain a quick overview of key data, such as patient counts or the availability of biospecimens. Conclusion: This work represents a first prototypical approach for an OSSE dashboard, demonstrated in an existing rare disease registry, to be further evaluated and enhanced in the future.

Keywords. rare diseases, registries, dashboard, data visualization, data aggregation

1. Introduction

The Open Source Registry System for Rare Diseases (OSSE) is a flexible framework to build web-based patient registries for rare disease research [1,2]. Since 2016, OSSE has been used for several rare disease patient registries, including the registry of the NEOCYST (Network for early onset cystic kidney diseases) consortium, funded by the German Federal Ministry of Education and Research (BMBF, FKZ 01GM1903F) [3]. Since 2018, 548 patients with rare hereditary cystic kidney diseases from >40 centers in Germany and Europe have been enrolled. The registry serves as the consortium's central clinical data platform; however, given its large data set (1,300 items in 44 forms), even simple analyses currently have to be performed in other tools.

Therefore, our objective was to develop a customizable OSSE dashboard to give users a quick overview of aggregated registry data, using NEOCYST as a first use case.

2. Methods

We assessed user requirements for the dashboard with four representatives from the NEOCYST consortium, including study nurses, researchers, and clinicians. Based on the

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resulting specifications, we created dashboard mock-ups which were further refined in recurrent meetings. In parallel, we implemented a general OSSE dashboard and filter and aggregation functions, in line with the role concept to ensure data privacy. These allow the retrieval of required data from the database and data aggregation across cases to create project-specific statistics. The aggregated data is sent to the user's web browser and rendered by the open source JavaScript library chart.js (version 2.9.3) [4].

3. Results & Discussion

The user requirements from the NEOCYST consortium are summarized in Table 1. The resulting dashboard prototype combines configurable generic components, available in any OSSE installation, and NEOCYST-specific views as per the user requirements, created through code modifications using the newly implemented functions.

Table 1. Requirements for a registry dashboard assessed with representatives from NEOCYST

#	Description
1	Number of patients at each study site, giving coordinators a quick overview over the contribution of each center and assisting with the validation of data at the central coordination office.
2	Number and type of samples in the consortium's biobank by selected diagnosis or genetic alteration, allowing users to quickly asses the availability of samples in a defined patient cohort.
3	Development of patient numbers over time by diagnosis, illustrating the progress of the study.
4	Mutated genes in the study population, giving users a more detailed overview of the patients not only by primary diagnosis but also the underlying gene defect.
5	Access to further study-related information, e.g., documentation guides or other resources.

With this work, we have developed a first prototype for an OSSE dashboard in the NEOCYST registry. Users directly benefit from an overview of key registry data, without the need to export data for analysis in a separate tool. Especially the improved visibility of biospecimens from different patient cohorts represents a major added value for NEOCYST users. As a next step, the usability and contents of the dashboard will be systematically evaluated and enhanced, also in other OSSE installations.

At this stage, project-specific dashboard statistics still have to be defined in the code. We will therefore develop an OSSE user interface to allow the creation of dashboard contents for users without IT knowledge in the future and extend the general OSSE dashboard with additional statistics considered of general interest.

In conclusion, a dashboard to visualize selected registry data represents a useful extension of OSSE, as demonstrated here in the registry of the NEOCYST consortium as an example of a multi-center study with a large data set.

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