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Extending the Austrian National EHR System with Patient-Reported Outcome Data

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Abstract. The Austrian national Electronic Health Record system ELGA is a population-based infrastructure for health data. However, to date, it does not include patient-reported outcomes. In this paper, we describe on-going work on extending ELGA with patient-reported outcome data. This will be done by linking ELGA with the infrastructure of the Health Outcomes Observatory (H2O) initiative. The focus will be on using ELGA's identifier registry for H2O patients and making H2O outcome data accessible in ELGA via an existing ELGA document type for telemonitoring.

Keywords. patient-reported outcomes, H2O, national EHR system, Austria

1. Introduction

The incorporation of patient-reported outcomes (PROs) in routine care is recognized as an important aspect to optimize health systems towards value-based care and to improve patients' care experience and engagement [1]. Europe's current health systems mostly do not promote enough the use of PROs in clinical care [2]. The Health Outcomes Observatory (H2O) initiative [3] will establish an ecosystem to provide PROs for informed health care decision-making to patients, care providers, scientists, and other stakeholders including industry researchers. It will deploy a federated infrastructure for data collection, management, and analysis that will include clinical outcomes as well as PROs, initially in Austria, Germany, the Netherlands and Spain. An upscaling to further European countries is planned later on. In accordance with H2O's goal to offer an integration into national health care ecosystems, the Austrian partners within H2O are exploring how H2O could be linked with Austria's national Electronic Health Record (EHR) system ELGA [4]. First focus points will be the use of (i) the ELGA identifier registry for identification of H2O patients, accessed via Integrating the Healthcare Enterprise (IHE) Patient Demographics Query (PDQ), and (ii) an existing ELGA document type for telemonitoring to make H2O PROs accessible in ELGA, utilizing Health Level Seven (HL7) Clinical Document Architecture (CDA).

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2. Methods

A requirements engineering process will be conducted that accounts for needs of all stakeholder groups. Austria utilizes sector-specific digital personal identifiers (bPK), which prevent cross-sector tracing. The healthcare-specific personal identifier (bPK-GH) is stored in ELGA to support the identification of patients in ELGA-specific tasks. When a new patient is registered in H2O, its identity management component will request the bPK-GH from ELGA via IHE PDQ. ELGA features a telemonitoring document type for storing PROs collected within H2O by means of sensors or questionnaires. We will examine how the H2O dataset can be best fed into the structure of the ELGA document type. This will include a transformation from the HL7 FHIR format used in H2O to the HL7 CDA format used in ELGA. Whereas the FHIR resources and profiles to be used have not yet been defined, the CDA telemonitoring document type has been released by ELGA in 2021. Clinical outcomes and PROs will be stored in a structured and standardized way to enable their effective analysis.

3. Results, Discussion, and Conclusion

The described work is in its early phase. Currently, we assess preferences of different stakeholder groups including organizational and legal requirements for accessing the mentioned identifiers through the H2O infrastructure and storing PROs as telemonitoring documents in ELGA. Another current focus within H2O is the design of the diabetes-specific questionnaires to be used in the first prototype planned for 2022. H2O aims to collect and incorporate PROs along with other health outcomes into healthcare decision making at personal as well as population level and across multiple European health systems. It strives for an integration into existing eHealth infrastructures wherever possible. ELGA provides health data sharing for around 97% of the Austrian population and enables care providers as well as citizens to access cumulative health data. Linking H2O to ELGA will extend the latter's current focus on clinical data with the new dimension of PRO data and at the same time allow H2O to benefit from the well-proven functionalities of an established national EHR system.

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