

Patient Generated Digital Health Data: An Example from the Finnish Neuro Registry

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Abstract. Patient generated health data is increasingly supported by mobile devices, health applications and patient interfaces, through which it can be shared and forwarded to healthcare professionals (HCPs). The Finnish Neuro Registry, integrated into electronic patient records (EPRs), was developed to monitor neurological disorders. It has numerous sub-registries for specific neurological diseases such as multiple sclerosis (MS) and epilepsy. This article focuses on the patient interface for people with MS (pwMS) as well as the digital seizure diary for people with epilepsy. Patient generated data through the patient interface is displayed on a HCPs' interface to facilitate patient participation in clinical decision making. As of September 2024, the Finnish MS registry, operational for ten years, includes data from 12,633 patients, covering approximately 90% of Finland's MS population. The Finnish epilepsy registry, operational for less than three years, now includes data from 18,325 patients. The existence of the Finnish Neuro Registry is based on close collaboration between healthcare professionals, information technology (IT) specialists, and patients, highlighting the importance of teamwork in achieving seamless data integration and optimizing outcomes.

Keywords: Multiple sclerosis, epilepsy, registries, patient generated data, PROM, shared decision making

1. Introduction

Patient-centeredness is a cornerstone of treatment and monitoring of chronic diseases. Today patient generated data (PGD) is recognized as a key element to enable patient participation in clinical decision making. This participation is increasingly supported by mobile devices, health applications and patient interfaces, through which PGD can be shared and forwarded to healthcare professionals (HCPs) [1,2]. Shared decision making (SDM) is a procedure where a decision is made jointly with the patient and the HCP

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based on the best available medical evidence as well as the patient's preferences and values [3,4].

High-quality registries are essential for monitoring long-term illnesses. The Finnish Neuro Registry consolidates several sub-registries for chronic neurological diseases, including multiple sclerosis (MS), myasthenia gravis (MG), movement disorders such as Parkinson's disease, epilepsy, spinal muscular atrophy, Duchenne muscular dystrophy, and Huntington's disease. Among these, the Finnish MS registry has included a patient interface, called MyMS, since 2017, allowing patients to contribute health data on their symptoms, quality of life and overall wellbeing supporting patient-centred treatment decisions [5]. Recently, self-reporting for non-invasive neuromodulation therapies began in October 2023 through the StellarQ My mobile app.

In this article, we describe the MyMS patient interface in the Finnish MS registry and especially the visualization of PGD on the HCPs' interface for facilitation of SDM. Furthermore, the epilepsy seizure diary is described as an example of a mobile application producing data on ecological momentary assessment of patients with epilepsy.

2. Methods and Results

2.1. The Finnish MS and Epilepsy registries – clinicians' interface

The Finnish MS registry is a browser-based registry for public health care organizations, which is integrated into the hospital's electronic patient records (EPRs). The HCPs log on to the registry via the hospital's EPR system with a single-sign identifier, which redirects them to the registry view of the patient. If the hospital so chooses, the structured patient narrative is transferred to the neurology interleaf of the EPR, which enables single recording. The development of the registry, the steering committee, and the clinical features of the registry are described elsewhere [6]. The MS registry is used in 17 out of 21 of Finland's wellbeing services counties including all five university hospitals. As of September 2024, the number of patients in the MS registry is 12,633 covering approximately 90% of up-to-date evaluations of the number of pwMS in Finland. The Epilepsy registry has been available for less than three years and it is in use in four out of 21 wellbeing services counties, with partial data coverage, including data on 18,325 patients. The registries are available in Finnish, Swedish, and English.

2.2. The Finnish MS registry – MyMS patient interface

The patient interface for patient-reported experience measures (PREMs) and outcome measures (PROMs) is available for all who have been registered in the Finnish MS registry. MyMS is an information secure service where the patient logs in by means of electronic identification such as online banking credentials [5]. It offers a user-friendly and graphically illustrative interface for reporting PREMs and PROMs in addition to disease-specific information. MyMS displays PGD on the HCPs' interface (see Figure 1). As of September 2024, there is data on 2360 pwMS in MyMS.

MyMS includes background data such as employment and lifestyle factors as well as standardized PROMs on disease severity, quality of life, and symptoms such as fatigue and cognitive problems. The detailed list of data elements in MyMS is described previously [5].



Figure 1. The Finnish MS registry. PREMs and PROMs are displayed on the clinicians' interface. PREDESS = Patient Reported Expanded Disability Status Scale, EQ-5D = Euro Quality of life – 5 Dimensions, SDMT = Symbol Digit Modalities Test, FSMC = Fatigue Scale for Motor and Cognitive Functions, MSNQ = Multiple Sclerosis Neuropsychological Questionnaire (see [5] for more details; illustrative photo)

2.3. Epilepsy seizure diary as an example of a mobile application

One of the latest developments in the Finnish Neuro Registry and PGD is the epilepsy seizure diary (Figure 2), accessible through a mobile application. Data entered into the epilepsy registry by HCPs, including seizure types, epilepsy syndrome, and disease etiology, are automatically visible on the patient's interface. When recording seizure types in the registry, HCPs use terminology familiar to the patient and align it with the updated international classification of epileptic seizures. The diary only allows the patient to log seizures based on predefined seizure types. The 'My Epilepsy' section of the diary provides patients with information about their epilepsy type, syndrome, and etiology, ensuring they have a comprehensive understanding of their condition. Seizure entries made by the patient are available in real time in the epilepsy registry, giving HCPs an up-to-date view of the patient's condition when they log into the registry. Accuracy of the recorded seizures is confirmed through discussions between the patient and the HCP. Verified seizures are displayed graphically on the epilepsy registry's timeline, alongside information on medication and possible stimulation therapies.

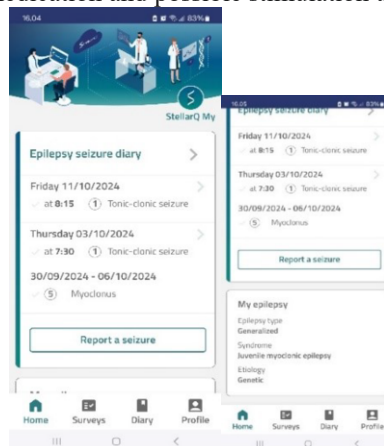


Figure 2. Epilepsy seizure diary. Patients can report and track epileptic seizures over time, providing healthcare professionals with patient perspective and enabling the evaluation of treatment effectiveness.

3. Discussion

Epilepsy and MS are so-called preference sensitive conditions with multiple equally efficacious treatment choices, each differing in, e.g., side effects, administration routes, or suitability for family planning. It is therefore evident that individual treatment planning requires PGD for SDM [7,8]. According to a European survey published in 2019 [9], only seven out of 19 identified MS registries included patient derived measures. The Finnish MS registry is the only one displaying PGD on the clinicians' interface. Furthermore, the Finnish epilepsy registry now has a mobile seizure diary application that shows seizures on the HCPs' interface where also other seizure-related data, such as changes in medications, are displayed. The piloting of the seizure app is just beginning. There are reports of various mobile apps for MS, but to our knowledge none of them are transferring PGD to a MS registry or integrated in hospital EPRs [10].

Health technologies such as patient interfaces and apps can be useful tools for self-management for people with chronic conditions such as MS and epilepsy if they are accepted by patients, and if they have sufficient eHealth literacy skills [11,12]. eHealth literacy refers to an individual's capability to utilize and produce health information digitally [13]. Regarding the present study, it is of note that people with epilepsy or MS are shown to have adequate eHealth literacy skills [7,14].

MS registries are actively used in many European countries [15] and the need for further development is recognized worldwide [16]. Registries provide real-world data on the disease course, effectiveness, tolerability, and safety of treatments [15,16]. Epilepsy registries have mainly been kept by each centre, in each country, without harmonization, but recently the European Reference Network for Rare and Complex Epilepsies (ERN EpiCARE) has started to build a common registry [17]. Along with the development of clinician-based registries, the need to implement PROMs and PREMs to promote patient autonomy, SDM, and cost-effective, personalized care has been recognized [7,18].

To conclude, the Finnish Neuro Registry includes patient interfaces for MS and epilepsy, which display data on an HCPs' interface. The registries have been developed in close collaboration with HCPs, IT specialists, and patients. This kind of collaboration ensures the effective development and implementation of patient monitoring systems, enabling seamless data integration and, ultimately, improving patient outcomes.

4 Acknowledgment

The research was funded by the Strategic Research Council (SRC) established within the Academy of Finland (no. 31213358415 and 31213358418).

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