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Patient Input into the Electronic Health Record: Co-Designing Solutions with Patients and Healthcare Professionals

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Abstract. Patient-generated health data (PGHD) is the person's health-related data collected outside the clinical environment. Integrating this data into the electronic health record (EHR) supports better patient-provider communication and shared decision-making, empowering patients to actively manage their health conditions. In this study, we investigated the essential features needed for patients and healthcare providers to effectively integrate PGHD functionality into the EHR system. Through our collaborative design approach involving healthcare professionals (HCPs) and patients, we developed a prototype and suggestion, using Estonia as a model, which is the ideal approach for collecting and integrating PGHD into the EHR.

Keywords. Patient-generated health data (PGHD), electronic health record (EHR), electronic medical record (EMR), digital health, data integration, patient-centered care, patient empowerment

1. Introduction

Access to personal data through a patient accessible EHR (PAEHR) is an emerging trend that is highly valued by patients and positively affects their treatment results [1]. The Nordic countries are recognized as being at the forefront of developing and using digital health [2].

In addition, digital health technologies are increasingly relevant for many patients, especially those with chronic conditions, offering opportunities to collect essential health data directly from a person to support both patients' self-management and healthcare professionals (HCPs) in making the right treatment decisions and providing more

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patient-centered care [3]. Patient-generated health data (PGHD) is data that is collected by patients outside the clinical environment [4]. The increased use of PGHD is reflected in the new European Health Data Space initiative, in which patients will have more autonomy over their data by enabling them to insert information, correct inaccurate data, and receive details on the utilization and purpose of their data [5].

In the NORDeHEALTH project [6], we recognized that despite the willingness of persons with chronic conditions, there were no trustworthy procedures and standards to integrate PGHD into the PAEHRs in any of the four countries participating in the project.

In Estonia, high blood pressure (BP) and cardiovascular diseases in general, together with their complications, rank first among the causes of morbidity and death [7]. Cohen et al. [8] have demonstrated the importance of home BP measurements in treating hypertension.

In this paper, we explored what functionalities are crucial to patients and HCPs for the implementation of PGHD functions in the EHR. Our aim was to develop a prototype and suggestion, using Estonia as a model, which is the ideal approach for collecting and integrating PGHD into the EHR. We had two objectives: (1) describe HCPs and patients' needs for PGHD and (2) prototype development through user-centered design processes, including close collaboration with patients and other relevant stakeholders.

2. Methods

To achieve the objectives, we explored through interviews and workshops both patients' and HCPs' views of PGHD and its use in the care process. We used the design thinking framework that follows the overall flow of understanding, exploring, and materializing [10].

2.1. Interviews

In December 2022 and January 2023, seven interviews were conducted with HCPs in both primary and secondary healthcare services who worked closely with patients with hypertension and/or type 2 diabetes. Interviewed HCPs were general practitioners, family nurses, cardiologists, endocrinologists, and physiotherapists. The criteria for the inclusion of HCPs were that they work with the target patient groups in their practice.

In February and April 2023, 13 interviews were conducted with patients with high BP and/or type 2 diabetes. A purposive sampling approach was used to select interviewees. This method was chosen to align the sample more closely with the research goals and objectives. Patients were involved voluntarily through patient networks, which were the Estonian Diabetes Association and the Estonian Patients' Association. The inclusion criteria were a diagnosis of type 2 diabetes and/or hypertension and the necessary digital competence to communicate via email. To understand the problem, we conducted semi-structured in-depth interviews, asking HCPs and patients about currently used BP and blood glucose measurement practices, the pros and cons of these practices, and their thoughts on future developments in this field. The recorded interviews were transcribed and anonymized by H.S. Interviews were analyzed using qualitative content analysis [11]. The interview questions were used to guide the first stage of the analysis (deductive approach). Following the formation of data clusters through deductive analysis, an inductive analysis was carried out, where new themes emerged during the

data analysis process. Based on the HCPs interviews, 5 patient personas were created: 3 personas with hypertension and 2 with type 2 diabetes.

2.2. Workshop

In May 2023, we conducted a guided workshop with HCPs with open-ended discussions to get input from HCPs regarding the prototype and suggestion creation. The workshop's goal was to co-design a PGHD BP measurement prototype with the HCPs, discuss the examples, and add corrections if necessary. A total of 16 people participated in the 90-minute workshop: 4 family doctors, 8 family nurses, and 4 employees of TalTech eMedLab.

3. Results

3.1. Interview results

Interviews with HCPs revealed that the measurements made by the patient and related self-reported information are precious but still mostly missing data for the HCPs. The process of how the self-measuring BP data collection is done right now on paper is very inconvenient for HCPs. Moreover, HCPs mentioned the practice of copying paper documents into their EMR and how certain data is not shared.

Patients indicated that it is important for them to understand why they must measure their BP and insert this data into the PAEHR. Writing on paper has been convenient for them because it is often immediately available. Thus, for them it was important to insert health data as easily as possible. None of the patients had experienced transferring their data to the app via Bluetooth. However, at the same time, it was mentioned that automatic data transfer would probably be the most convenient option for them.

3.2. Workshop results

As a result of the workshop, a BP measurements prototype was created for the standardization and safe entry of patient data into the PAEHR. According to the HCPs, the prototype must be very simple and not cause additional work or unnecessary information. The BP and blood sugar graphs should be in two or three colors and should show mainly numbers and graphical lines, with only a minimum of additional information. However, if there is a significant difference in BP numbers, free text should be added to describe the cause (e.g., lifestyle changes).

3.3. Suggestion for a flow chart

Based on the interviews and collaborative workshop, we co-designed suggestions for the future on how the capture of PGHD should be implemented into the HCPs workflow. As patients will have more access to their health data, PGHD (e.g., BP) is essential in addition to the data collected by the HCPs as it reflects a significant part of a person's health condition.

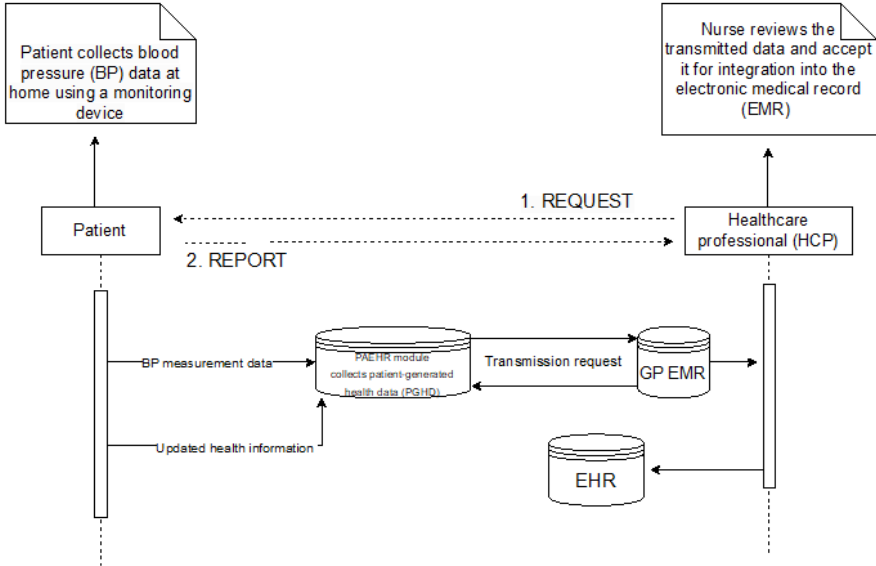


Figure 1. Continuous data flow chart of HCPs workflow with PGHD for high blood pressure patients. The data flow in the Estonian example shows that the process should seamlessly fit into the patients' and HCPs' data capture process. The upper part represents two actors, and the lower part is the technical data flow solution. The figure does not address devices or other technical capabilities at this initial stage.

The process begins with the patient measuring their BP at home (Figure 1). The measured BP data is inserted into the PAEHR module, serving as the primary platform for patients to record and monitor their health data. Following data input, the PAEHR generates a transmission request to the GP EMR. This request signals that the patient's BP data is prepared for transmission. Within the GP EMR, nurse reviews the transmitted data. The accepted data is approved for storage in the EHR system, ensuring that the patient's updated health information is evaluated by HCP and is easily accessible for future needs. In addition, if the HCP identifies a significant difference in the BP measurements, the patient should add free text to describe the cause of the abnormal measurements, the cycle repeats. The GP EMR can potentially reduce the fragmentation of medical information and enhance medication reconciliation by consolidating patient medical data into a centralized repository. It facilitates a non-linear, interactive process between GPs and patients, which is especially beneficial for individuals with chronic illnesses.

4. Discussion

Through our collaborative design approach involving HCPs and patients, we developed a suggestion on how to make collecting PGHD seamless and trustworthy. Secondary use of patient clinical data adds new valuable and so far, underutilized information for health decisions, can improve health management, decrease healthcare expenses, and support successful clinical research [12]. Consents for secondary use of clinical data are managed through the Patient Portal. Most of the previous studies on PGHD and its integration into the PAEHR have discussed the importance of PGHD, standards, and integration, but

research on the reuse of this data for decision-making purposes remains insufficient [13]. Our proposal is unique as we recommend integrating PGHD easily into the PAEHR, allowing continuous data reuse if needed. During the work, HCPs did not express more doubts about PGHD data quality except the fact that they wanted to review it, and, if there is uncertainty, to ask patients to describe in free text where it came from (e.g., changes in lifestyle).

5. Conclusions

Despite the potential benefits of PGHD for the monitoring and management of chronic health conditions, there remains a need for improved tools and processes to integrate this information into PAEHRs seamlessly. The goal is to empower patients, facilitate better communication between patients and healthcare providers, and contribute to informed decision-making in managing chronic health conditions [14].

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