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Design Considerations for the Use of Patient-Generated Health Data in the Electronic Medical Records

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Abstract. Patient-generated health data (PGHD) is of growing interest to physicians, particularly if they are integrated in the electronic medical record (EMR). Concerns about how to manage vast amounts of PGHD and potential liability issues have limited their use. Based on interviews with specialists, we present types of PGHD, workflow processes and needs. We then discuss consideration for how to manage PGHD with approaches for analyses to detect abnormal results, and present implications for alert systems and visualization requirements in multi-patient views.

Keywords. Patient-generated health data (PGHD), alerts, patient-reported outcome (PRO)

1. Introduction

With the widespread adoption of smartphones, tracking devices and connected devices, patients collect vast amounts of data about their health. Patient-generated health data (PGHD) include several types of data. Some require patient inputs such as clinical parameters (e.g., blood pressure or glucose measurements), or patient-reported outcomes (typically surveys or questionnaires). In fact, the definition of PGHD by the Office of the National Coordinator for Health Information Technology (ONC) [1] also includes health data collected from family members or other caregivers. Healthcare providers may encourage their patients to collect and share their health data to help manage a medical issue. They may send questionnaires before or after a medical visit or may want to help patients with their self-management.

Since PGHD can potentially generate vast amounts of data, providers worry about receiving too much data from their patients, and not have time to process these data, with concerns about subsequent liability for abnormal findings. Artificial intelligence can provide solutions to handle the increasing amount of data made available by PGHD, by detecting anomalies and sending alerts, for example.

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In a prior paper, we focused on liability and interoperability issues of PGHD [2] in this paper, we aim to explore design considerations to detect and manage abnormal results and to create an adapted alert system. We therefore interviewed healthcare professionals to identify the PGHD of interest and their usage to analyze how types of data will determine different models of interpretation to create adapted alerts.

2. Methods

Our understanding of PGHD is based on individual semi-structured interviews and focus group with healthcare professionals from several contexts of care. These encounters were conducted to understand clinicians' use and needs for PGHD, as well as concerns in implementing this kind of data in our EMR.

We asked clinicians about the type of data they wish to collect about their patients, how they intend to collect it, how they would like to see it in relation to the EMR, and their concerns about collecting PGHD. We conducted a thematic analysis of the collected transcripts.

We report our findings in the results and discuss the feasibility of the different solutions for a safe and reliable integration into the EMR. We reviewed the various approaches to managing PGHD, analyzing possible triggers for alerts (e.g., thresholds, pattern recognition, and trends with various methods of analyses). We conclude with design implications for visualization and alerts systems for PGHD.

3. Results

From June 2021 to December 2021, we encountered a total of 14 physicians, 2 nurses and one project manager from 12 specialties: oncology, cardiology, infectious diseases, nephrology, diabetes and endocrinology, psychiatry, family (ambulatory) medicine, emergency medicine, general surgery, neurosurgery, pain specialists (from anesthesiology) and telemedicine. Four individual semi-structured interviews and two focus group were conducted.

The thematic analysis identified the following topics: types of PGHD, visualization in the EMR, alerts and workflow.

3.1. Types of data and data collection

Four specialties currently already use patient questionnaires (paper or electronic surveys), two only use questionnaires for research, and five divisions are still considering how to implement patient-reported outcome (PRO) tools. None of the current electronic questionnaires are integrated with our EMR. Some divisions review patient-generated data on websites or import them from patients' devices (e.g., glucose measurements).

Five specialties anticipated 2 to 10 new patient questionnaires in the near future, which could target 40 patients in medical specialties to 3000 in pre-hospital consultation patients per month. All participants were interested in questionnaires for their patients, with different objectives: these ranged from preparing a medical visit, following up after a visit or for research purposes. For example, the oncologists use a questionnaire to assess for side-effects of chemotherapies [3].

In addition to use questionnaires, four specialties were interested to collect (or plan to collect) PGHD from a variety of devices to adapt the care for their patients. Glucometers, continuous glucose devices, scales, pedometers, etc. were commonly considered sources of PGHD.

3.2. Workflow and management of PGHD

All participants agreed that management of PGHD would require a new workflow. An initial workflow is required to send the right questionnaire to the right patient at the right time. The clinicians needed to be able to "prescribe" the questionnaire or have an easy process to ensure that a given patient would receive the right questionnaire. Patients may need support for technical or clinical assistance with the questionnaire. After the patient submits her responses, there needs to be another process to ensure that the responses are seen, whether the results are in the EMR or not.

Finally, results of the questionnaire need to be analyzed to determine the appropriate action: urgent responses need immediate attention such as contacting the patient or alerting the patient's doctor. It may result in a new appointment, lab test, or imaging. The urgency of managing the responses will depend on the responses the patient has given. The whole questionnaire may be a clinical score, which needs to be interpreted as a single entity, other questionnaires may have key questions that may require an adapted response. An example of key question is a self-assessment of a suicidal risk, which may require an urgent response.

3.3. Visual design and dashboards

All participants agreed on the need for a summary view of patients and results. Medical assistants or other providers who work with PROs need to have an overview of sent and answered questionnaires to follow up on their patients in a multi-patient view. This is the initial dashboard requirement, which should also show the various alerts that we discuss below. Visual design needs to distinguish process alerts (no answer, for example) from content alerts, with varying levels of urgency.

When abnormal findings of low urgency need to be seen at the patient's next visit, the alert needs to be visible at the right time for the given user: our interviewed physicians were very concerned about alert fatigue and information overload, leading to missed information. Therefore we address considerations for designing alerts in the next section.

4. Discussion

4.1. Considerations for designing alerts

Some parameters have simple interpretations, whereas other need to integrate additional information for interpretation. When an abnormality is defined by a single question, or a final score, an alert system is easily designed, triggered by the abnormal result. The subsequent question is to define who needs to receive the alert. When we asked each physician how to design the alerts and who to target, we received different responses, according to the degree of urgency. These are summarized in Table 1.

Table 1. Dispatch of alert and their degree of urgency

Degree of urgency	Example	Action	Alert receiver
Extremely urgent	Recurrent chest pain after myocardial infarction	Call for an ambulance	Medical assistant or nurse, Doctor
Urgent	Recurrent hypoglycemia at 6pm over 3 days, when driving home from work	Contact the patient, make an appointment if needed with the doctor, or send to ER	Medical assistant or nurse
Potentially urgent	Presence of suicidal thoughts	Contact the patient	Medical assistant or nurse
Needs action	Glucose at 16 mmol/l for 3 days	Make an appointment with doctor	Medical assistant or nurse
Highlight for next appointment	BP of 170/100 on a single occasion	To discuss at next planned visit	Nurse or doctor at next visit
Useful to know	Patient submitted a response or uploaded PGHD	Review when possible	Medical assistant or nurse
Absence of response	No response after a week	Resend an invitation for a questionnaire or to upload data	Medical assistant

These are examples of alert designs for PGHD, which can vary widely depending on the existing process of patient care in a division: some clinicians may want to be alerted directly for values that are less urgent. The heterogeneity in physicians' expectations and processes emphasize the need for customized design to ensure efficiency and patient safety.

4.2. Analysis of PGHD and alerts

Although PGHD can be represented as numerical data, thresholds for concern may vary from a person to another, even for a given parameter. Absolute values may suffice to trigger an alert for some parameters, while others need to assess the trend over time.

Table 2. Type of PGHD parameter and their modality

Parameter	Modality	Examples
PHQ-2* (clinical score to screen for depression)	1 threshold	If score ≥ 3, depression is likely
Pain scale (Visual analog scale)	Multiple thresholds	<4: mild pain 4<pain<6: moderate pain >6: severe pain
Specific question (e.g., suicidal thoughts)	Positive answer	Alert if "Yes"
Blood pressure (systolic)Δ	Multiple threshols	> 180 mmHg if single value >160 if sustained <90
Weight ¥	Upper threshold	Weight gain of ≥2 kg over 3 days
Glucoseα	Upper and lower threshold	Sustained values or recurrent pattern over ≥3 consecutive days (both > 15 mmol/l or < 3.5 mmol/l)

*Patient-health questionnaire
Δ Blood pressure values could be combined with symptoms to improve detection or pattern recognition (e.g., with chest pain)
¥ Example for individuals with heart failure Thresholds vary depending on target population
α Thresholds need to be adapted for older patients, or if on insulin or certain anti-diabetic medication

When the PGHD parameter has a binary interpretation (Y/N or one threshold), and does not require additional considerations, the alert depends on the degree of urgency. When the PGHD parameter has 2 thresholds or more, the urgency of the alert may vary depending on the threshold. Severe pain will be an urgent alert, while mild pain may be useful to consider at the next visit, for example. Yet other variables need to be assessed for patterns of concern, such as recurrent hypoglycemia over several days. Other considerations for these parameters are the target population, or concurrent elements (other symptoms, medications, or comorbidities, for example). PGHD of data that are interpreted as variations or trends can also use differential analyses or regression models, especially if the threshold is a constant (e.g., weight gain of 2 kg in 3 days). Examples of variables, modalities for analysis are presented in Table 2.

For PGHD parameters like blood glucose measurements, which typically result in many data points, or even continuous data from continuous glucose measurements are interpreted as patterns. In these cases, more advanced analyses using machine learning such as temporal analysis can be considered, and even adjusted by users who can confirm or infirm the results of the analyses.

4.3. Potential pitfalls

PGHD can result in vast amounts of data. Advanced models, such as machine learning systems can help to monitor and adapt alert thresholds, but should be use with caution given the possible consequences. While analyses are invaluable to avoid missing key results, overuse of analysis methods can lead to over diagnosis and alert fatigue. These would then lead to decreased efficiency for patient safety, with a possible increase in healthcare use (visits, tests and anxiety for patients).

5. Conclusion

Our exploration of approaches to integrate PGHD into the EMR emphasized the need to consider the type of data, which will guide the design of alert systems. These alerts must be implemented within local workflow processes, which will define the alert targets. Visual design needs to be adapted to each context, degree of urgency and distinction for process and content alerts. Finally, designing multi-patient views, and a simplified process to allow clinicians to specify which PGHD is needed for a given patient are also needed for all the participants interviewed.

References

[1] Shapiro M, Johnston D, Wald J, et al. Patient-Generated Health Data - White Paper. *Prep Off Policy Planning, Off Natl Coord Heal Inf Technol Res Triangle Park NC RTI Int* 2012; 35.

[2] Blondon K, Ehrler F. Integrating patient-generated health data in an electronic medical record: Stakeholders' perspectives. *Stud Health Technol Inform* 2020; 275: 12–16.

[3] Pearce A, Haas M, Viney R, et al. Incidence and severity of self-reported chemotherapy side effects in routine care: A prospective cohort study. *PLoS One* 2017; 12: e0184360.