

Acceptance barriers of using patients' self-collected health data during medical consultation

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Abstract

Patients increasingly collect health-related data using mobile health apps and sensors. Studies have shown that this data can be beneficial for both clinicians and patients if used during medical consultations. However, such data is almost never used outside controlled situations or medical trials. This paper explains why the usage of self-collected health data is not widespread by identifying acceptance barriers perceived by clinicians, patients, EHR vendors and healthcare institutions. The identification of the acceptance barriers relied on a literature review, a medical pilot, a co-design and focus groups using diabetes as a case.

Keywords

Acceptance barriers, self-collected health data, consultation.

1 INTRODUCTION

The explosion of mobile health (mHealth) applications, wearables and sensors allows patients to collect an increasing amount of health- and lifestyle-related data [1-3]. Previous studies have shown that this data can be useful during consultations, for both clinicians and patients [4-6]. However, it appears that such data is rarely used outside of controlled studies, despite the fact that 60% of patients are open to giving their doctors real-time access to their health- and lifestyle-related data [7].

This paper is part of the 'Full Flow of Health Data Between Patients and Health Care Systems' project, supported by the Research Council of Norway (number 247974/O70), which focuses on integrating self-collected health data into consultations in Norway. This paper explains why the usage of self-collected health data in medical consultations is not more widespread beyond controlled studies by identifying, categorising and analysing acceptance barriers perceived by clinicians, patients, electronic health record (EHR) vendors and healthcare institutions (HI). Healthcare institutions are organisations providing healthcare services, including but not limited to patients care and equipment or materials used for the provision of health care.

2 METHODS

2.1 Identification of acceptance barriers

Three complementary approaches and sources were used for identifying the acceptance barriers to the usage of self-collected health data during medical consultations.

The first, primary sources of information were the results of two studies we conducted: one literature review regarding systems that integrate self-collected health data into EHRs [8] and one medical pilot involving sharing patients' self-collected health data with clinicians during

consultations [9]. The review allowed identification of technical issues regarding the introduction of self-collected health data into consultations, while the medical trial focused on patients' and clinicians' expectations regarding the usage of patient-gathered data during consultations.

The second source of data relied on ten focus groups that involved 1) system architects and system owners of the Norwegian Directorate of eHealth (NDE, the central administration responsible for the eHealth infrastructure in Norway under the direction of the Ministry of Health and Care Services) and 2) system architects and product owners of the three largest Norwegian EHRs, namely DIPS (secondary healthcare), Infodoc Plenario and System X (primary healthcare). Each focus group lasted between 1 and 3 hours. The goal was to study the challenges regarding the integration of patients' self-collected health data in general into the national health infrastructure and into Norwegian EHRs (e.g. standardisation, security). The EHR vendors are partners in the FullFlow project. We used brainstorming and go-round methodologies supported by open-ended discussions during these focus groups to balance creativity and problem-solving tasks.

The third approach consisted of the organisation of a co-design workshop involving five patients with type 1 diabetes, two endocrinologists and two nurses specialising in diabetes. This co-design workshop was also part of broader study focusing on facilitating collaboration in diabetes care [10]. The participants were recruited through our in-house mobile self-management application, Facebook and by our partner, the University Hospital of Northern Norway (UNN). We received an exemption from the local ethics committee to perform this study (REK Ref. 2018/719), and acknowledgement by the Data Protection Officer at UNN (Ref. 2018/4027-4). Three sessions comprised the co-design workshop: (a) the

first with patients only, (b) the second with clinicians only and (c) the third with all participants. Each session lasted half a day, and sessions (a) and (b) were held simultaneously in different locations before session (c). We used different methodologies during these sessions, namely writing round-robin (all participants answer a question on paper simultaneously and then present the answers in turn orally to the group) and brainstorming. The methodologies permitted a balance of creativity and problem-solving tasks while lowering pressure on the participants by allowing them to speak in turn. We used this co-design workshop to gather feedback on opportunities, acceptance barriers and interface design ideas generated by both patients and clinicians using scenarios based on the experience of the participants (e.g. diabetes patients sharing the data they collect with their clinicians). A more thorough description is available in another article [10].

This paper focuses on reporting the acceptance barriers. The acceptance barriers were identified when a challenge, an issue, or a negative thought related to the usage of self-collected health data during medical consultations was either expressed by the participants or described by a study.

2.2 Data categorization

The first author defined a taxonomy inspired by the work of Boonstra and Broekhuis [11] to present a global overview of the current barriers to acceptance of the introduction of self-collected health data into medical consultations. The taxonomy contains six categories:

- *Financial*: the cost issues related to the development, maintenance and usage of an information technology system supporting the collection, transmission and consultation of self-collected health data. Cost is the most important factor related to the failure of eHealth interventions [12].
- *Workload and workflow*: the impacts or potential impacts on clinicians' workload and clinical workflow. Workflow-related issues are one of the main factors in failure of eHealth interventions [12].
- *Technical*: the challenges related to the usage of hardware and software tools for collection, transmission and display of self-collected health data during consultations. This category includes the barriers related to technical capabilities of the physicians, patients and suppliers operating the tools.
- *Time*: the factors leading to increased time to perform a task.
- *Trust*: the factors influencing the ability to perceive the usage of self-collected health data during consultation as trustful, on both the personal and social interaction levels.
- *Legal*: concerns related to formal laws, such as privacy or security.

The next section presents the identified acceptance barriers using the taxonomy defined above.

3 RESULTS

Table 1 lists the identified acceptance barriers and the actors concerned by them, following the methodologies described in the previous section.

In total, 21 acceptance barriers were identified. The *technical* category contains the most acceptance barriers, with seven (33%) listed. The *financial*, *time*, *cognitive* and *workflow* categories follow with three (14%) barriers each. The *legal* category contains two (11%) barriers.

In total, the actors mentioned these barriers 33 times. Clinicians were the most concerned, with 15 (46%) barriers, followed by the HIs (nine barriers, 27%), the EHRs (five barriers, 15%) and the patients (three barriers, 12%). The next sections present the acceptance barriers in detail.

Table 1 List of identified acceptance barriers to the usage of self-collected health data by patients during consultations and the actors who identified them. Tax = taxonomy, Fin = financial, Tec = technical, Tim = time, Tru = trust, Leg = Legal, Work = workload and workflow. Actors: H = healthcare institutions, C = clinicians, P = patients.

Tax	Acceptance Barriers	Actors
Fin	Investment costs	H/EHRs
	Maintenance costs	H/EHRs
	Training users (clinicians)	H
Work	Lack of practice/training	C
	Lack of incentives/participation	C/P
	Heavier workload/reorganisation	C/H
Tec	Lack of skills	C
	Lack of data reliability	C
	Complexity of usage	C
	Obsolescence of the system	H/C/P/ EHRs
	Lack of software and hardware reliability	H/C/ EHRs
	Lack of standardisation	H/EHRs
	Too much data	C
Tim	Time to learn	C
	More time per patient	C
	Tracking data is a burden	P
Tru	Need to control	C
	Lack of belief	C
	Interference with doctor-patient relationship	C
Leg	Privacy/security of the data	P/H
	Missing legal context of usage	C/H

3.1 Financial acceptance barriers (Fin)

HIs and EHRs were uneasy about potential cost increases related to the support of self-collected health data because, firstly, they have to invest in new information technology (IT) services or systems for supporting this new type of data and ensuring portability and interoperability [13] and, secondly, because they must address the challenges linked to the amount of self-collected health data available: system availability, continuity and scalability [14], which require yet more investment. Furthermore, the on-going maintenance of these new functionalities would constitute a new source of cost. HIs were also concerned by the need to organise courses for clinicians to ensure that they correctly use these new functionalities. For these institutions, this represents a *double cost: clinicians have to spend time learning new tools instead of providing clinical services*.

3.2 Workload and workflow acceptance barriers (Work)

Three barriers to acceptance were identified corresponding to this category. Firstly, clinicians expressed their lack of practice and training in the usage of self-collected health data for providing medical services. They were *dubious regarding their own skills for using this type of data correctly and were afraid that this data will distract them during consultations*, resulting in a degradation of the quality of their medical services. In some cases, patients' situations might even regress [15].

Secondly, clinicians and patients mentioned that there could be a lack of incentives and participation. Clinicians' motivation to use self-collected health data in consultations may be weakened by their lack of confidence and the absence of clinical standards and procedures for the usage of this type of data. Patients could be demotivated because daily registering of health data is time consuming and reminds them that they are sick [16]. Moreover, some patients, being afraid to be judged on their self-management performances, could be refractory to participate.

Thirdly, clinicians and HIs were concerned that the introduction of self-collected health data into consultations would increase the workload of the clinicians, who are already overwhelmed by their work schedules, which, in turn, could degrade their quality of life [17, 18]. The effect could be even greater if patients' systems provide a real-time communication channel [4], and it could also impact the current medical workflow because HIs and clinicians must integrate this new source of data into their procedures and use them side-by-side with existing data, such as laboratory results. In addition, there are currently no clear standard approaches to using such data. Clinicians were also afraid of becoming *'technical support employees'* for helping patients use their systems and collect their data correctly.

3.3 Technical acceptance barriers (Tec)

The first technical barrier mentioned was the clinicians' lack of skills and awareness regarding the usage of patient-

oriented technologies, such as wearables, sensors or applications. Therefore, they were *doubtful regarding which solution is adapted for which patient for a given situation*.

The second barrier concerned the lack of reliability of the self-collected health data, which was perceived by clinicians as less reliable than laboratory results due to multiple factors [19-22] (e.g. defective patients' sensors, operator error when manually registering). Clinicians perceived this barrier to be important.

The third barrier, which concerned the clinicians, was the complexity of systems that patients present in consultations, mainly due to a lack of a common graphical interface because of the wide variety of applications, wearables and sensors available [1, 2]. Clinicians are unable to learn how to use all such systems considering their daily clinical responsibilities and limited schedules.

The fourth barrier mentioned by all actors was the obsolescence of IT systems. Patients and clinicians were afraid of failing to keep up with the constant changes of the ecosystems (new products rolled out while others become unsupported). EHRs and HIs were concerned that their IT systems could not support the evolution of healthcare informatics standards [23].

The fifth barrier to acceptance mentioned was the lack of software and hardware reliability, which concerned HIs, clinicians and EHRs. Hardware reliability refers to ability of the hardware to perform its functions as intended. For instance, patients' systems could be defective in registering data or become disconnected from the internet and unable to share data, and data stored in HIs' systems could be unavailable due to the amount of data to manage. Software reliability issues mainly relate to the software used for consulting data, which could be unstable due to the amount and variety of data collected [24]. This situation would make work difficult for clinicians, who may not have the most suitable tools for using self-collected health data during consultations.

The sixth barrier was the lack of standardisation of the patients' systems. Most systems are proprietary, specialised (e.g. disease-oriented) and require specific equipment for accessing the data. For instance, Glooko [25] focuses on diabetes and provides hardware and APIs for accessing the data, while Tytocare [26] proposes general tools requiring their own platform for accessing data. EHRs and HIs must therefore rely on multiple external actors for providing self-collected health data to clinicians. This lack of standardisation inhibits semantic interoperability between patients' and EHRs' systems to be achieved.

The last barrier concerned the abundance of self-collected health data gathered by the patients. Clinicians were afraid they would *'not be able to separate relevant data for providing adapted care from data noise'* using their existing tools.

3.4 Time acceptance barriers (Tim)

Clinicians perceived the time-related barriers as the most important, as they already feel they are time-starved.

These barriers are further affected by multiple barriers mentioned earlier. In general, clinicians felt they would have to spend a lot of time learning how to use self-collected health data for providing relevant medical services, redesigning their workflows to include this new type of data and investigating patients' systems and the data collected. This task would be difficult to handle considering the wide variety of systems available, their non-standardisation and the different data types available.

Moreover, clinicians perceived that they would need more time per patient. Clinicians must determine whether the systems used by the patients and the data collected is useful, considering the various patients' situations. Clinicians would have to deal with the emotional state (e.g. anxious, depression), motivation and skills of patients regarding the usage of self-management technologies. For instance, the platform proposed by Kumar et al. [24] requires 45 to 60 minutes of configuration per patient before any consultation can happen.

Patients mentioned that they might not register regularly for long periods, considering that collecting data can be *'time consuming and bothersome.'* Moreover, they would prefer to focus on managing their current situation in real-time instead of retroactively analysing their actions. However, they mentioned that *'thoroughly registering for a short period, one or two weeks, could be feasible to address or to investigate specific health issues, with the help of clinicians.'*

3.5 Trust acceptance barriers (Tru)

The first acceptance barrier mentioned by the clinicians in this category was related to the need to control the medical workflow. Clinicians do not fully trust the procedures of the data collected by patients, believing that they are less reliable than laboratory results. They therefore expressed the need to know how the data is registered (i.e. which methodology, which sensor) and at what intervals.

There was also a lack of belief in the usefulness of the data by some clinicians, who believed that self-management should not interfere with classical healthcare. Moreover, demotivated patients may not use mHealth or collect data reliably, let alone fully follow providers' self-management recommendations. Therefore, other types of interventions would be needed for them.

The last point concerns interference with the doctor-patient relationship. Empowering patients and permitting them to bring their self-collected health data to a consultation could create difficulties in the doctor-patient relationship, considering that clinicians prefer a more traditional approach, relying on their training and their working colleagues [27].

3.6 Legal acceptance barriers (Leg)

Patients and HIs mentioned that the regulations regarding privacy and security in the sharing and usage of self-collected health data could represent a barrier to acceptance, especially since the implementation of the General Data Protection Regulation (GDPR). The GDPR requires 1) explicit consent to use self-collected health

data, 2) a transparency notice explaining what data is used and 3) full access to the stored data for patients [28]. However, the application of the regulations would be difficult as most of the patients' systems are proprietary..

Another point was related to a lack of legal context for the usage of self-collected health data in medical workflows. To our knowledge, there is no juridical protection for clinicians, patients or HIs regarding the usage of this type of data. For instance, clinicians are neither permitted to nor prohibited from making a medical decision based on patient-collected health data. However, clinicians mentioned that it would be safer to use self-collected health data only as an input to the investigative process, rather than making medical decisions at that stage of the medical examination.

4 DISCUSSION

Regarding the defined taxonomy, we defined two categories not listed in the original taxonomy of Boonstra and Broekhuis [11]: workload and workflow, and trust. The latter is inspired by the original psychological category which concerns acceptance barriers related to personal issues, knowledge and perceptions of clinicians regarding the adoption of EHR systems. The former is a grouping of two original categories: change process and organisational acceptance barriers. The changes rendered the classification process easier and the created categories fit better the identified acceptance barriers in this study. The other original categories (financial, technical, time and legal) were unchanged.

Concerning the representativeness of the population, only a limited number of patients with type 1 diabetes were involved in the medical pilot (n=20) and in the co-design (n=5). These patients were already using self-collected health data to manage their conditions and were aware about collaborating with their clinicians using this data. Similarly, a limited number of clinicians involved in the co-design study (n=4) is not representative of all medical specialties. The clinicians were also exposed to self-collected health data by patients during medical consultations (e.g. consulting logs or messages sent by patients). Therefore, the acceptance barriers identified in this study could be more pronounced for a population not exposed to self-collected health data and to technology in general [29]. However, the literature review and the open-ended discussion in the focus groups involving system architects and owners permitted to expand the focus to any type of patients' self-collected data in the process of identifying the acceptance barriers.

In addition, there is a lack of clear documentation about the potential return on investment (ROI) or cost-benefit ratio (CBR) when using self-collected health data in medical workflows due to the lack of large-scale studies. Therefore, the introduction of self-collected health data in consultations are still not documented as a clear advantage, in terms of ROI or CBR, compared to public interventions [30], telemedicine [31], mobile health clinics [32] or healthcare command centres [33]. Similarly, the improvements in patients' quality of life when using self-

collected health data in a collaborating way with clinicians is uncertain and depend on the context of the study [34].

5 CONCLUSION

This paper reported that a significant number of acceptance barriers are perceived by clinicians, patients, EHRs and HIs that prevent broad usage of self-collected health data during medical consultations.

According to the HIs and EHRs, the most critical acceptance barriers were related to costs and to the changes in medical workflow required by the introduction of self-collected health data into consultations.

Clinicians perceived time consumption and the lack of reliability of the data as the main acceptance barriers, while patients considered the burden of collecting health data to be a nuisance.

However, it appears that most of the acceptance barriers were connected to each other. For instance, the lack of standardisation of systems sharing collected health data would force clinicians to spend time learning each system, which would contribute to increased costs, with the need for courses, which in turn links to an added complexity of usage.

Proposing a solution for sharing self-collected health data addressing all these acceptance barriers therefore presents a challenge, and more research is necessary.

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