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Insights on Patient-Generated Health Data in Healthcare: A Literature Review

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Abstract

Through the growing spread of eHealth applications, users are now able to easily generate vast amounts of personal, health data. However, to this date it is unclear what the role of patient-generated health data (PGHD) in healthcare is, based on an IS perspective. This promising source of personalized patient data holds the big opportunity of improving diagnosis and treatment of diseases. Therefore, we address this topic using a structured literature review. Based on an analysis of 131 papers, we provide insights into three major literature streams: (a) PGHD collection methods, (b) integration of PGHD into clinical workflows and (c) influence of PGHD on patient clinician interactions. Our findings present the current research on these three literature streams and highlight the benefits and challenges of PGHD. This paper contributes to the understanding of PGHD usage in healthcare from an IS viewpoint and provides a starting point for future IS research.

Keywords: patient-clinician interaction, health informatics, shared decision-making, self-tracking, patient-generated data

Introduction

With about 53000 mHealth (mobile Health) Apps in the iOS Appstore (Appfigures 2021a) and about the same amount in the Google Playstore (Appfigures 2021b), many individuals are generating big amounts of personal health data. In a clinical context, this data has the potential to improve the diagnosis and treatment of various -often chronic- diseases, such as hypertension or diabetes (Shah and Garg 2015; Turner et al. 2021). In the form of "patient generated data" (PGD) or "patient generated health data" (PGHD), this data reflects patients' everyday behaviors including physical activity, mood, diet, sleep, and symptoms (Choe et al. 2018). Whereas the usage of PGD has been common for several decades in the personalized treatment of chronic diseases (Cahn et al. 2018), new technologies like smartphones and wearables in combination with health apps enable personalized precision treatment for an even wider spectrum of diseases such as mental health disorders (Burgermaster et al. 2020; Danis 2016; Hartmann et al. 2019). The role of PGHD[1] in the clinical context is therefore highly relevant and timely, but not yet clarified.

In addition to the improvement of the treatment of diseases, PGHD enable an aspect that has so far been overlooked: active patients' participation in the treatment process. Medical research, such as the one on the chronic care model (CCM) (Wagner et al. 1996) highlights the advantage of involving patients in the diagnosis and treatment of their diseases and thus supporting patients' self-management. Educating patients to learn skills and tools to monitor their symptoms encourages self-monitoring. This prevents an excessive focus on the negative, which may contribute to patient anxiety (Purtzer and Hermansen-Kobulnicky 2016). PGHD empowers patients not only to be more involved in their treatment, but also to actively contribute to their health. Based on PGHD clinicians and patients create a value-co-creation environment with the goal of finding the best therapy based on shared decision-making (Kim and Lee 2017).

Due to the emergence of technology, studies on potentials and usage of PGHD in the clinical context have increased in recent years. However, we lack a clear understanding from an IS perspective as to how PGHD should be integrated into the clinical workflow to fully support patients and clinicians in their interaction. While there are many opportunities and benefits of PGHD in the clinical context, we need to ensure that the collected data is appropriately incorporated and used in the clinical workflow without creating an additional burden for patients and doctors, e.g. technostress (Ye 2021) or information overload (Rodriguez et al. 2019). In order to look at the potentials of PGHD in the clinical context from an IS perspective, we conducted an extensive literature review on PGHD and derived research findings as well as research gaps for IS research. In the review process, we were guided by the following research questions (RQ):

- RQ1: What are state-of-the-art methods for collecting PGHD?
- RQ2: What are the main benefits and challenges when integrating PGHD into clinical workflows?
- RQ3: How does the introduction of PGHD change the patient-clinician interaction? What are the drivers and challenges of this change?

The article is structured as follows: In the following section of this article, we describe the design of the literature review. Then we present the identified main findings and introduce the current state of PGHD usage in healthcare on the basis of our three postulated research questions. In the present article we further present different types of PGHD collection methods, illustrate challenges and benefits of the integration of PGHD into clinical workflows and show that the introduction of PGHD can cause a shift in patient-clinician interaction before, during and after consultation. Finally, we discuss potentials for the usage of PGHD in the clinical context from an IS perspective and present detailed guidelines for future research on the potentials of PGHD for diagnosis and treatment of patients.

Design of the Literature Review

When conducting the literature review, we followed guidelines from established IS literature (vom Brocke et al. 2009; Webster and Watson 2002). We started by defining a search string able to cover publications from different disciplines. We decided to search for the terms "patient generated data" and "patient generated health data" in the fields title, abstract and keywords in the SCOPUS database. The inclusion of both PGD and PGHD in the search string was necessary because during our research we discovered that both terms are frequently used to describe data collected by patients. Whereas PGD describe personal data that "are uniquely defined and seen as important by the patient, that can occur dynamically and provide personal indicators of health status" (Hong et al. 2018), PGHD describe a more precise form of PGD and are by definition health-related data created, recorded, gathered by the patient, including health and treatment history, symptoms, lifestyle choices, and other information (Shapiro et al. 2012). To consider the interdisciplinary nature of the topic, we decided against a restriction based on outlets and conducted a search on the complete database. We conducted the search on January 13, 2022 and found 460 articles based on the defined keywords.

[1] For reasons of simplification, we always refer to PGHD and PGD when mentioning PGHD (if not stated differently)

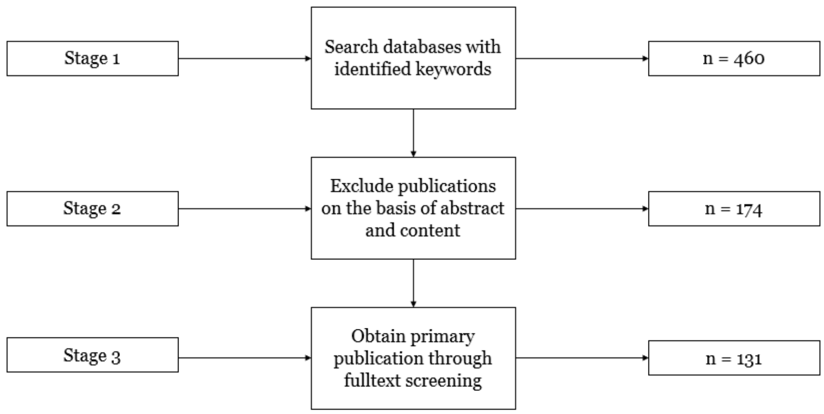

Figure 1. Selection Process

In accordance with the guidelines underlying our research, we then conducted a careful selection of relevant articles. Figure 1 represents a visualized representation of our selection process. We started by establishing the following criteria for the inclusion of relevant articles, of which at least one should be fulfilled: (a) usage of PGHD to improve a diagnostic or treatment process (b) coverage of the topic of usage/integration of PGHD into clinical workflows and/or (c) description of the collection and/or processing of PGHD. We then screened the titles and abstracts of all articles, resulting in a reduction of the sample by 286 articles which did not meet our inclusion criteria (data sample size n= 174 articles). We then studied the full text of the remaining 174 articles and subsequently identified 131 relevant articles that matched at least one of our inclusion criteria.

In the next step we assessed the characteristics of the relevant articles. Table 1 provides an overview of the identified most relevant outlets. This table contains the outlets that returned the most hits and selected articles in the search. When we first started our literature review process, we initially investigated the Senior Scholars' Basket of Eight (Association for Information Systems 2022) for relevant literature on the topic of PGHD, as this collection represents the most important collection of outlets for Information Systems research. In this collection, the search for our selected keywords did not prompt any results. Therefore, due to the interdisciplinarity of the topic, our first major aim was to identify the main outlets for research on PGHD. When looking at the list of outlets of the search prior to screening, four of the five outlets with the most hits are journals that belong to the medical informatics category. Most prominent in the list are the journals published by JMIR Publications. Both journals included in the list (Journal of Medical Internet Research and JMIR mHealth and uHealth) are journals that cover the discipline of eHealth management. For this discipline we used the ranking provided by Serenko et al. (2017). Here, the aforementioned journals are ranked as either A+ or A Tier outlets.

The journal "Studies in Health Technology and Informatics" is also mentioned in the ranking but was excluded. Further key outlets in our literature review were the Journal of the American Medical Informatics Association (A+) and the Surgical Infections outlet (unranked). The only key outlet that was represented by a conference is the "Conference on Human Factors in Computing Systems". To rank this outlet we followed the CORE2021 Conference Ranking (CORE 2021), which ranks this conference as A* conference.

Following our guidelines, we then coded the identified 131 articles along several dimensions that are relevant to our research questions. We coded the articles along (1) their thematic association (e.g. integration of PGHD into clinical workflows), (2) the covered disease (e.g. diabetes) and (3) the collection method (e.g. active collection or passive collection). We present these results in form of a concept matrix in Table 2. In the following, we go into detail about the findings of each topic.

Outlet	Journal/Conference Ranking	Search	Hits	Selected
Journal of the American Medical Informatics Association	A+	TITLE-ABS-KEY ("*patient generated data*") OR TITLE-ABS-KEY ("*patient generated health data*")	19	11
Studies in Health Technology and Informatics	unranked[2]		19	5
JMIR mHealth and uHealth	A		17	8
Journal of Medical Internet Research	A+		14	6
Surgical Infections	unranked[2]		11	2
Applied Clinical Informatics	A		9	5
Conference on Human Factors in Computing Systems – Proceedings	A*		8	3
Basket of Eight	/		0	0
Other	/		363	91
		Total	460	131

Table 1. Overview of the Main Identified Outlets in the Literature Search Process

Results

In this section of the literature review we summarize the insights retrieved from the selected articles. The coding of this literature review is visualized in Table 2. The first category of the concept matrix is *Thematic Association*, which illustrates the topics of the three research questions we postulated at the beginning of this literature review (data collection, workflow integration, patient-clinician interaction). We present these findings in detail below, structured on basis of this dimension.

The second category *Disease* in Table 2 provides an overview of the diseases that were covered in the individual papers. This category reveals that several diseases are represented more frequently than others. We found that diabetes (type 1 and 2), cancer, cardiovascular diseases and mental health disorders are the most commonly mentioned diseases in PGHD literature. The coding along the category *Collection Method* revealed that passive collection methods (e.g. wearables, smart sensors) almost double the number of active collection methods (e.g. observations of daily living). This prevalence may stem from the introduction of wearables and their increased usage in recent years. For the *Disease* category, most publications address diabetes. This can be attributed to the historical use of PGHD in the context of diabetes treatments.

[2] Unranked for Serenko et al. (2017)

Article	Thematic Association			Disease					Collection Method	
	Data Collection	Workflow Integration	Patient-Clinician Interaction	Cardiovascular Diseases	Diabetes	Cancer	Mental Health	Other Diseases	Active Collection Methods	Passive Collection Methods
Alpert et al. (2020)		X								X
Austin et al. (2020a)	X			X	X					X
Austin et al. (2020b)			X					X	X	
Bourke et al. (2020)		X	X							
Burgermaster et al. (2020)		X			X				X	X
Burns et al. (2019)			X							
Chung et al. (2016)		X	X						X	X
Cohen et al. (2016)	X	X			X				X	X
Cresswell et al. (2019)		X								
Dixon and Michaud (2018)			X					X		
Hartmann et al. (2019)	X						X		X	X
Holt et al. (2020)		X								
Hong et al. (2018)	X		X					X	X	
Hussein et al. (2021)		X								
Kumar et al. (2016)		X	X		X					X
Lindroth et al. (2018)			X							
Marceglia et al. (2017)		X								
Ng et al. (2019)	X	X	X				X		X	X
Nittas et al. (2019)	X	X		X	X	X	X	X	X	X
Panda et al. (2020)			X			X		X	X	X
Piras (2019)	X								X	
Plastiras and O'Sullivan (2018)		X							X	X
Raj et al. (2017)			X		X				X	X
Rodriguez et al. (2019)		X		X					X	
Saudek (1989)	X				X					
Vaughn et al. (2019)			X					X		X
West et al. (2018)	X	X		X	X	X	X		X	X
Whitney et al. (2018)		X						X	X	
Wu et al. (2020)		X					X		X	X
Ye (2021)		X						X		
Zhang et al. (2019)	X		X							
Other	44	67	31	22	48	29	21	15	49	83

Table 2. Concept Matrix - Perspectives on Patient Generated Health Data

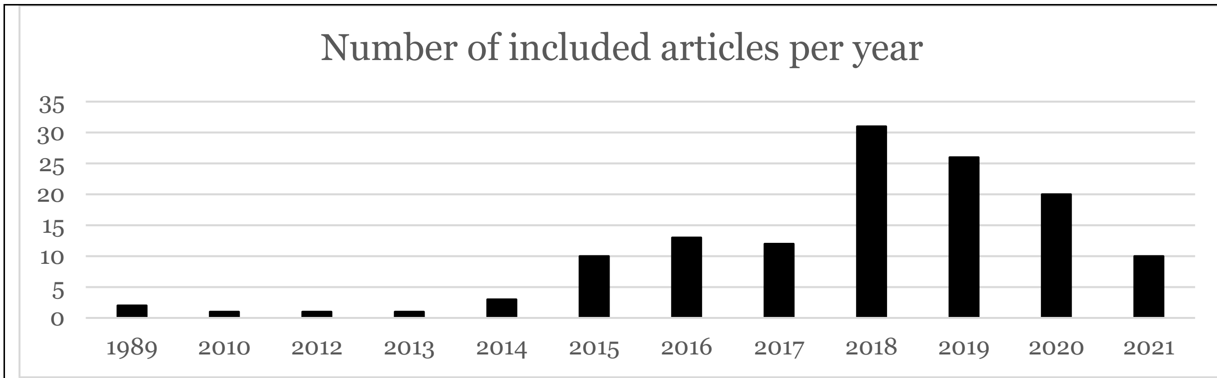

Figure 2. Number of included articles per year

An initial quantitative analysis of the included articles shows that research on the topic of PGHD has increased significantly since 2015 and peaked in 2018 (Figure 2). From our results we conclude that the rise in publications on PGHD is to be associated with the rising omnipresence and growing ease of use of smartphones and smart devices. Additionally we identified several main research trends within PGHD research. These main research trends include articles on the topics of smartwatches, which are discussed in 11 articles, smartphone and smartphone enabled collection of PGHD (discussed in 54 articles) and the integration of PGHD in the "Electronic Health Records" (EHR) (discussed in 29 articles). In the following sections we present detailed insights into the described literature streams by means of our defined RQs.

PGHD Collection Methods

In this section we address the literature stream on collection of PGHD and aim to answer RQ1 "What are state-of-the-art-methods for collecting PGD?". We found articles describing the data collection process of PGHD that date back as early as 1982 (White 3rd et al. 1982). In these early articles, PGHD was primarily introduced for diabetes patients who self-documented their health conditions and discussed the same with their clinicians on a regular basis (Saudek 1989; Ziegler et al. 1989). The authors describe early collection methods that usually contained handwritten files that were collected and generated by patients and then transformed by clinical staff to be put into early clinical computer systems (Saudek 1989). These early methods for collecting PGHD are mostly associated with diabetes care and their comorbidities like hypertension, which is reflected by the multitude of articles found on these diseases with PGHD association (see Table 2).

With the omnipresence of smartphones since the early 2010s, there has been a shift in PGHD collection methods. Whereas data collection was initially rather time and resource consuming for patients (Piras 2019), modern technologies enable the collection of large amounts of data without requiring active involvement of the patient. To shed more light on this aspect, we divide PGHD collection methods into two sub-categories: (a) active collection methods and (b) passive collection methods. There are benefits and challenges to implement these types in patient care settings, which we describe in the following paragraphs.

Active PGHD collection methods are collection methods that require patients to actively engage in data input. Examples for this type of collection method are blood glucose level measurements, blood pressure level measurements and questionnaires (Nittas et al. 2019). A major benefit of active collection methods is the increased patient engagement in their therapy (Austin et al. 2020a). This benefit stems from the insight that better treatment outcomes can be achieved if patients are engaged in aspects of their own care (Danis 2016). Through the higher levels of patient engagement, active PGHD collection methods can promote increased motivation for collecting data in patients (Nittas et al. 2019).

Passive PGHD collection methods are collection methods that do not require patients to actively collect data themselves; instead, the data collection is outsourced to technological devices that generate PGHD automatically (Nittas et al. 2019). Passive collection methods are mostly covered through smartphones or wearables, such as smartwatches and other body worn devices (Heintzman and Kleinberg 2016). The sensors in these devices track signals such as step count, heart rate and sleep (Ng et al. 2019).

A common problem we faced during our literature review, which arises with the introduction of PGHD into clinical workflows, is the trustworthiness and quality of the collected data (Huba and Zhang 2012; Nittas et al. 2019; Reading and Merrill 2018; West et al. 2017). This problem is further amplified when patients show surprising or unusual symptoms. In this case, the introduction of passively collected data from wearables like smartwatches can shift the clinician's attitude in a positive way as it is harder for the patient to alter the collected data (Alpert et al. 2020). In addition to this benefit, passive collection methods can reduce the burden on the patient when collecting data automatically through wearables (Piras 2019) and continuous data collection (Ng et al. 2019). With the reduced tracking burden, passive PGHD collection methods enable data collection from patients who normally would not be able to collect data actively (Bove 2019). While passive collection methods may have less patient engagement in comparison to active methods, patients who might not be able to actively collect data may still feel more involved.

Expanding the spectrum of diseases that are observable through PGHD collection

With new collection methods a greater variety of diseases can be treated through the usage of PGHD collection methods. Table 2 presents an overview over the four most common diseases that are addressed in the included articles of this literature review. Most interestingly, chronic cardiovascular diseases, diabetes (type 1 and 2) and cancer are the most common comorbidities with depression (Glassman, 2007; Roy & Lloyd, 2012; Smith, 2015) within our mental health dimension. While especially chronic cardiovascular diseases (Marquard et al. 2013) and diabetes (Saudek 1989) have been treated through PGHD for a longer period (also in combination) as the above mentioned active collection methods allowed to collect data for these diseases, the idea of treating mental health problems (Ng et al. 2019) and recovery among patients undergoing cancer operations (Panda et al. 2020) through the usage of PGHD is not new but has only emerged in recent years with the introduction of passive collection methods.

Technology-supported PGHD collection methods not only facilitate the data collection process, but also enable the collection of new kinds of data that give more insights into patients' daily life, so called "Observations of Daily Living" (ODLs), enabling the usage of PGHD for a greater variety of diseases. ODLs are defined as data that complement traditional signs and symptoms of disease and highlight the personal experience of health and disease (Brennan et al. 2010). ODLs can be collected actively or passively. ODLs reflect feelings, thoughts, behaviors, exposures, and actions. Examples include counts of nights of adequate sleep, the time frame between eating broccoli and experiencing bowel movement, missed workdays, medication taking, phone usage or frequency of diaper changes. Types of ODLs can have a wide range and may be personalized to specific patients' needs (Brennan and Casper 2015). Benefits of ODLs are a richer picture of the patient's daily life that might be relevant for case management to the clinician (Piras 2019). Use cases of ODLs often include personal tracking, improvement on the basis of the results (Cohen et al. 2016) and improvement in the communication with clinical care. This means that ODLs represent a language that patients can use to communicate experience in a self-explanatory way (Hong et al. 2018).

Integration of PGHD into Clinical Workflows

In the previous section we highlighted the multitude of PGHD collection methods. While these methods on their own are well implemented, the current eHealth Apps' ecosystem consists of mostly disconnected applications that miss connection to standardized medical protocols (Akram et al. 2017). This causes problems when integrating PGHD into clinical workflows or EHR (Cohen et al. 2016; Lewinski et al. 2019). Based on more recent studies, the integration of PGHD into clinical workflows is still in its infancy (Hussein et al. 2021). To provide a better understanding of the integration of PGHD into clinical workflows, this section provides insights into different ways for PGHD workflow integration; discusses typical problems and barriers when using PGHD in medical practices and suggests solutions to overcome them. With this chapter, we thus aim at answering RQ2. We divide this section into several parts: First we give insights into common challenges and barriers of PGHD integration into clinical workflows. Then we look at the technical integration of PGHD into clinical workflows through technologies like EHR. Lastly, we give insights into how the integration of PGHD changes the actual workflows of clinicians and healthcare professionals.

West et al. (2018) investigated the common barriers for integration of PGHD into clinical settings. This article classified the barriers along three areas: (a) data collection and data use, (b) data interpretation and (c) the use of PGHD in clinical practices. The main barriers for each area contain (a) incomplete data and unclear reliability of these data sets, (b) irrelevant data, inadequate or non-existing interoperability with healthcare information systems and insufficient time to review the data, and (c) unclear patient motivation, limited data use by practice or training as well as the possibility that the collected PGD might not be considered concrete evidence for a diagnose. These barriers illustrate that while modern technologies facilitate the collection of PGHD, the resulting high volume of data may be more difficult to accommodate in the clinical workflow.

Additional challenges for the integration of PGHD surround the time consumption of data integration into EHR. These challenges have not just become topical in recent years, but have been around for a longer period of time, especially in the context of diabetes and hypertension care (Marquard et al. 2013). Holt et al. (2020) revealed that clinicians often do not have sufficient time to prepare for a patient's consultation, thus they also struggle to find time to investigate PGHD beforehand and during the consultation. The review of the integrated data needs "one more click" in the system, which creates additional burden on the clinician as the system only grows bigger and therefore naturally becomes more complex. This time deficit, in combination with the increased amount of effort for the patient to put their collected data into the system, results in the clinician's concern that patients might label the clinician as "bad" (when not reviewing the data). These findings shed light on the potential negative sides of PGHD by indicating possible information overload and technostress on both the patient's and the clinician's part. While this seems to be a contemporary problem, this topic has not yet been considered sufficiently in research. Fourteen of the included articles consider clinician information overload (too much information)(Choe et al. 2018; Cronin et al. 2018; Reading and Merrill 2018; West et al. 2018).

While there are many barriers of integrating PGHD into clinical workflows, there is also research on how to overcome these barriers. Solutions on PGHD workflow integration need to offer opportunities to support both the clinician's and the patient's goals (Chung et al. 2016). For the clinician's side, approaches that use existing clinical infrastructure such as the EHR are the most viable solutions (Cohen et al. 2016). Currently the literature states that PGHD integration in doctors' offices is still handled by manually putting the data from printed sheets into the clinical computer system (Wu et al. 2020). A direct, passive and automated approach of data transfer into the clinical workflow seems feasible and has been shown to facilitate a more efficient provider workflow when integrating PGHD (Kumar et al. 2016). A solution for the integration of PGHD into clinical workflows through the usage of EHR contains the interoperability of the clinical platform with multiple disconnected sources (health apps)(Plastiras and O'Sullivan 2018). This can be achieved through an Application Programming Interface (API) that is able to integrate third parties' tools into the clinical platform(Akram et al. 2017). Several authors we included in our literature review created solutions to support the integration of PGHD into EHR based clinical platforms (Burgermaster et al. 2020; Karnati et al. 2021; Plastiras and O'Sullivan 2018). For example, Marceglia et al. (2017) created a solution that implements a specifically designed web-based platform that integrates EHR features, includes a workflow engine and supports a set of mobile apps and wearable devices for patient data collection.

In contrast to medically based solutions in recent years, more and more approaches that are usually situated in the information systems domain were introduced to solve problems with the integration of PGHD into clinical workflows. One example for this is the Approach by Burgermaster et al. (2020) that presents a nutrition suggestion system based on qualitative modeling of clinical reasoning and decision-making that combines PGHD with an expert knowledge base.

Lastly, the introduction of PGHD into clinical workflows can promote disease prevention. This shift targets the pre-consultation phase of patients. Here, PGHD has the potential to be used as a tool for early detection of diseases or disease related episodes (e.g. hypoglycemic episodes in diabetes) (Bhavnani et al. 2016). Through continuous long term PGHD tracking and self-management, it is possible to promote risk reduction and patient wellness (Hsueh et al. 2016). Successful and effective implementation of disease prevention holds benefits not only for the patients but also for the healthcare systems, businesses and society (Nittas et al. 2019).

Following our findings, we can draw the conclusion that PGHD needs to be further integrated into clinical workflows in order to truly have an impact. A first step towards better integration is to follow presented ways of integration of PGHD into EHR in a standardized way. This also includes standardization of data visualization (Kim et al. 2017). Data visualization is a key component to understanding the collected PGHD (Bourke et al. 2020). When faced with visualized PGHD, studies show that users prefer simple presentations (Whitney et al. 2018). In the next subchapter we discuss the role of PGHD on the patient-clinician interaction.

Patient-Clinician Interaction

In our thematic coding process, we identified multiple articles that take on different perspectives regarding the influence of PGHD on the patient-clinician interaction (Bourke et al. 2020; Burns et al. 2019; Kumar et al. 2016; Raj et al. 2017). In order to be able to use the full potentials of PGHD, it is essential to understand how the usage of PGHD reshapes the way patients and clinicians work together. With this section, we thus provide insights on the influence of PGHD on the patient-clinician interaction and aim at answering RQ3. In the following, we show how the introduction of PGDH into clinical workflows leads to multiple shifts in patient-clinician interaction and discuss these findings based on expectation theory, communication theory and shared decision-making theory.

Research on the influence of PGHD on patient-clinician interaction is deeply rooted in the expectation theory. When introducing PGHD into the diagnosis and treatment process, there are increased expectations from patients and clinicians regarding the accumulated data. From the patient's perspective, these expectations can be categorized into two categories: Expectations to support diagnosis and treatment and expectations to support affective needs (Chung et al. 2016). On the clinician's side the expectations on PGHD differ. The most common expectation on the clinician's side is getting a better idea of the patient's life in order to better understand patient goals and priorities (Chung et al. 2015) and facilitate discussions and targeted conversations with patients (Zhang et al. 2019).

If the expectations of patients and clinicians are equally met, the introduction of PGHD into patient-clinician interactions has the potential to positively influence consultations by providing a more accurate view on the changing disease and treatment response (Austin et al. 2020b). As a result, both patients and clinicians can use PGHD to identify problems about the ongoing therapy process and understand those problems to reach a decision about the next step in the therapy (Raj et al. 2017). Consequently, PGHD can improve patients' feelings about possible patient-clinician interactions (Hong et al. 2018). For providers, PGHD can aid diagnosis through more accurate symptom detection (Zhang et al. 2019) and reporting (Vaughn et al. 2019), improve patient-clinician communication and can reduce unnecessary consultations (Burns et al. 2019). Further studies show that clinicians that use PGHD provided by their patients passively communicate that they trust their patients' data. This higher level of trust was perceived as an even more respectful interaction by patients (Burns et al. 2019).

However, the introduction of PGHD might also result in unmet expectations on both the patients' and the clinicians' side. First, the patient-clinician collaboration might become effortful as the introduction of PGHD into the interaction can lead to unwanted differences in the risk perception of problems and the associated responses. While perception differences do usually not get recognized during patient-clinician interaction, they still do govern the problems that get discussed during such encounters. This means that while the patient and the clinician might be unaware of their changed expectations, there still is an immediate impact on decisions regarding the patient's treatment (Raj et al. 2017). Another possible negative effect of the patient's engagement with collecting data is that preconceptions about a possible diagnosis can arise. These preconceptions may cause problems in patient-clinician interactions when the final (doctor's) diagnosis is non-compliant with the patient's preconception. Still, these instances of self-diagnosis can be reduced when the data collection is initiated through a clinician and not the patients themselves (Burns et al. 2019).

Besides generating expectations, the introduction of PGHD also strongly affects the relationship and communication between patients and clinicians in multiple ways (Bourke et al. 2020). For example, the increased insights into the patient's disease through time helps the patient communicate about the disease (with clinicians and their relatives) (Dixon and Michaud 2018). The data itself in combination with possible more accurate symptom reporting (Vaughn et al. 2019) offers the clinician the opportunity to prompt questions about symptoms and facets of the patient's disease that they would not have asked if they did not have the data at hand during or before the consultation (Burns et al. 2019). During consultations with the patients, graphical summaries of the collected PGHD had an overall positive impact on the patient-clinician interaction. Through this tool, clinicians were able to point out special data points that patients might have forgotten (Austin et al. 2020b). Furthermore, PGHD improves the communication between clinicians and patients by coupling them with intuitive visualization, data delivery through EHR and automated triage (Kumar et al. 2016). Ultimately in this context, PGHD offers the potential to completely change the classic question-answer procedure during patient-clinician interaction as data generation is transferred into the patient's daily life (Lindroth et al. 2018). Lastly, the usage of PGHD facilitates the option for clinicians and healthcare providers to offer patients remote support (Burns et al. 2019).

A third strand of literature we have found regarding the patient-clinician interaction is research on the decision-making process based on PGHD. While this process is not new to diabetes patients, as insulin has always been self-administered according to the patient's readings, PGHD can improve decision-making in clinical environments by involving patients and thus supporting shared decision-making for many more diseases. Shared decision-making is defined by four main characteristics: (1) two or more involved parties (clinician, patient etc.); (2) both parties share information; (3) both parties take steps to build a consensus about the preferred treatment; (4) common agreement on the treatment is reached. Improved communication through the integration of PGHD between clinicians and patients can support shared decision-making (Austin et al. 2020b; Bourke et al. 2020). By introducing PGHD into clinical workflows, criteria (1) and (2) are fulfilled for shared decision-making and support criteria (3) and (4). In current research, the consensus is that shared decision-making is the preferred method for patients (Eliacin et al. 2015). Building on the improvement of shared decision-making, PGHD has been used to improve patient recovery after surgery. For this purpose, patients are monitored before and after surgery to identify their physical activity levels. These higher levels of patient monitoring to build a baseline for a shared decision-making environment proved to additionally benefit recovery monitoring and patient engagement (Panda et al. 2020).

Discussion

In this literature review we gave insights on the current situation of PGHD in healthcare systems. The multitude of articles deemed relevant for this literature review in relation to the number of articles prompted by our search string shows the importance of the topic. Table 3 illustrates the major findings of our literature review on the basis of the major benefits and challenges in the three presented major literature streams. Our first goal of this literature review was to identify the most important outlets for this interdisciplinary topic (Table 1). We found that studies on the topic of PGHD are mainly dominated by medical research outlets - see, for example JMIR Publications and the Journal of the American Medical Informatics Association (JAMIA). However, if we look at IS outlets, we find comparatively few publications (see for example Proceedings of the Hawaii International Conference on System Sciences (HICSS)). In fact, to the best of our knowledge, there is no article on PGHD in the Senior Scholars' Basket of Eight (Table 1). We argue that due to the emerging technical challenges as well as the need to look at PGHD from a technical and data-oriented perspective, PGHD is certainly a research strand to be discussed in IS research.

As mentioned above, we organized this article along the thematic dimension of our screening. This thematic dimension contained the three major literature streams we identified during the screening process of the literature review. This thematic association is supported by two further dimensions (the covered disease and the collection method) addressed in the chapters. With this literature review we aimed to answer three research questions also aiming at the thematic association of the articles included in this literature review. In the following paragraphs we want to discuss our findings on the basis of the presented research questions and postulate a research agenda for every research question based on the reviewed literature.

In this article our goal was to get an overview of state-of-the-art collection methods of PGHD. One finding is that new technologies change the way PGHD are collected. Research on PGHD illustrates how a transition from handwritten files (White 3rd et al. 1982) to modern solutions, represented through smartphones (Panda et al. 2020), platforms (Karnati et al. 2021) and wearables (Bove 2019) was achieved in the last decades.

While, through the growing digitalization during the last decades, collection methods have naturally become more technically sophisticated, we could also observe a shift from collection methods that require active patient engagement to a more passive way of data collection. These passive collection methods (mostly represented though wearables and smart sensors) can offer new opportunities to collect data, even from patients with chronic diseases that do not allow or restrict active tracking (Hartmann et al. 2019).

Literature Stream	Benefits	Challenges
PGHD collection methods	• PGHD results in patients' engagement into their own therapy (Austin et al. 2020a) • Multitude of PGHD and collection methods for different diseases available (Nittas et al. 2019)	• Patients must be motivated to collect data and share information about their daily living (Nittas et al. 2019; West et al. 2018) • Data collection can be a burden for different diseases (Piras 2019) • Results are heavily patient dependent (e.g. incomplete data) (West et al. 2018)
PGHD workflow integration	• PGHD enables for new ways of diagnosis and treatment in healthcare (Burgermaster et al. 2020) • PGHD leads to a shift in consultation and treatment planning (Burns et al. 2019)	• Accessibility (Usability of the PGHD integrated platform) of PGHD for clinicians must be ensured (Holt et al. 2020) • Data visualization of PGHD for clinicians is not standardized (Kim et al. 2017) • Integration of PGHD into Electric Health Records involves technical difficulties (Akram et al. 2017)
PGHD in patient-clinician interactions	• PGHD enables improved, personalized treatment of diseases (Cahn et al. 2018) • PGHD results in a shift in communication and role distribution in patient-clinician interaction (Bourke et al. 2020) • PGHD builds an improved base for a shared decision-making process in therapy (Austin et al. 2020b; Bourke et al. 2020)	• PGHD may result in possible expectations and preconceptions about diagnosis and treatment (Burns et al. 2019) • Clinicians must trust and use the provided PGHD (Burns et al. 2019) • Clinicians can be overwhelmed with the amount of data, which increases the risk for technostress and information overload (Holt et al. 2020; Ye 2021)

Table 3. Overview of Benefits and Challenges of PGHD in Healthcare

We think future research should focus on finding an equilibrium between active and passive tracking and collection of PGHD. Nittas et al. (2019) introduced the concept of "partially passive" approaches that involve both active and passive data generation and define this term as "anything that is not exclusively sensor-based, nor exclusively dependent on manual entries". We suggest that a mixture of active and passive collection methods can on one hand increase active patient participation through active data collection and on the other hand provide the benefits of passive data collection through all day data collection and more reliable data.

Further, we want to elaborate on our findings concerning benefits and challenges of integrating PGHD into clinical workflows. We looked at the subject from two different angles. First, we wanted to discuss the technical perspective. Here, we gave insights on the introduction of PGHD into EHR. Currently there are many efforts to ease this process. From our point of view it is to be considered that the usage of EHR is not very common at this point and that the problem of integrating and standardizing EHR in healthcare also has to be tackled (Jha et al. 2009). Secondly, we looked at how this integration changes the actual workflow. Here we uncovered the most important areas of improvement when integrating PGHD. During our literature review we found that a technical integration through EHR is not enough for clinicians to be able to use the provided PGHD in their consultations. We uncovered that in order for clinicians to be able to use the provided information, it needs to be easily accessible (Holt et al. 2020) and visualized in a way that makes it easily understandable (Akram et al. 2017). Because of these findings we think that future research should focus on the visualization of PGHD in clinical platforms. This enables more clinicians to include PGHD in their consultations with patients.

Lastly, we gave insights as to how the introduction of PGHD into clinical workflows can change patient-clinician interaction. From our perspective, this topic is of the highest importance as PGHD can change the classic distribution of roles in patient-clinician consultations. Overall, we showed that both parties can profit from the introduction of PGHD while there are still several challenges that must be solved in order to fully exploit the potential. We think that a solution to create a valuable shared decision-making environment is that both parties must change their behavior when bringing PGHD into the ecosystem. On one hand, clinicians must trust and consider PGHD in their diagnosis of diseases and therapy planning. On the other hand, patients must reduce their preconceptions of possible diagnosis in order to trust the clinicians' opinion. Based on these findings we propose that future research should address finding solutions to improve the behavioral problems that the introduction of PGHD into patient-clinician interaction involves.

Limitations

Our study, like all other studies, is subject to limitations. First, we would like to mention that the literature search might not cover all relevant studies due to the choice of outlets and keywords. Alternative terms for the concept of PGHD such as "Patient-Reported Outcomes" (outcomes that can be quantified as discrete measures to show how patients perceive their health and illness before and after treatment and over time. These include standardized questions and scales about treatment effects, symptoms, functional capacity, and health-related quality of life outcomes (Forsberg et al. 2015) might yield additional relevant articles. We therefore call for future research that covers the term "Patient-Reported Health Outcomes". Further, the coding process we conducted simplifies the result of the studies to make them comparable. We guided our results on the basis of the three main literature streams identified during the coding process (PGHD collection, integration of PGHD into clinical workflows and patient-clinician interaction through PGHD). Through this process, some insights might have been lost and are not represented in our results. Still, this means we gave the three main literature streams more attention, which lead to a greater level of details for our findings. Finally, the research gaps and challenges for future research that we defined from the analysis and synthesis of our findings might be influenced by the opinions and perspectives of the included authors. For this reason, there is a possibility that further open issues exist that are to be discovered in future work.

Future Research

In the discussions section, we already gave some insights on interesting topics for future IS research. In the following, we elaborate on three promising future IS research areas around PGHD. Table 4 provides an overview over the research gaps we identified with this literature review.

Firstly, we think it is necessary to obtain deeper insights into the willingness to collect and share PGHD from a patient's perspective. This topic has only been covered in one publication of this literature review (Turner et al. 2021). For the investigation of the sharing culture of patients it is important to get a broader view on barriers of PGHD based on data sharing theories, such as medical trust issues (Turner et al. 2021) or privacy concerns (Ng et al. 2019) and how we can overcome them. To make the best use of PGHD, it will be crucial to provide incentives for patients to voluntarily start collecting valuable data about themselves. Based on our findings, we think this can make a difference, especially for first consultations, as the treating clinician can get additional insights on the patient based on the patient's PGHD.

Secondly, a big concern by many clinicians in the studies we included in this literature review is the quality and trustworthiness of the collected PGHD (Huba and Zhang 2012; Nittas et al. 2019; Reading and Merrill 2018; West et al. 2017). For future research, it is important to provide further insights into how checks and control mechanisms can be included in the collection process to improve tamper resistance in the used methods (Abdolkhani et al. 2018). This way, we think an improved trust foundation can be built between the patients and clinicians which ultimately shall lead to more involvement of PGHD in patient-clinician interactions.

Literature Stream	Future Research Topic
PGHD collection	• Patient willingness to share data with clinicians through the usage of applications or platforms. • Improved Trustworthiness and Quality of Data through increased tamper resistance. • Improved deployment of active and passive PGHD collection methods for personalized needs.
PGHD workflow integration	• Approaches to improve the spread of EHR usage in healthcare • Reduction of potential Information Overload and the connected burden on clinicians. • Improved data visualization of PGHD in clinical platforms to improve usability and accessibility for clinician. • New Roles in healthcare to support better integration of "new" technologies and data work.
PGHD in patient-clinician interactions	• Mechanisms to increase trust in PGHD by clinicians. • Further improvement of shared decision-making environment for patient-clinician interaction.

Table 4. Future Research Topics for the Investigation of PGHD in an IS Context

Thirdly, we uncovered that the problem of information overload through the introduction of PGHD into clinical workflows can also become a major problem. With the introduction PGHD clinicians are concerned to be more likely to overlook "something" through the amount of data they are presented (Sanger et al. 2016). Risks for clinicians include a higher risk of burnout through the additional burden and time consumption (Ye 2021). With only 17 articles mentioning "information overload" and one article (Ye 2021) mentioning "technostress", we think this topic should also be considered in future research in the context of integration of PGHD.

Lastly, in addition to the presented trends in research on PGHD we call for IS research on the necessary changes in skills due to the introduction of PGHD in the clinical context. Choe et al. (2018) proposed the introduction of a new role in healthcare. This new role called "the informatician" can help with finding actionable insights in heaps of life-data and being capable of discovering and visualizing correlations and causations in data. In the included articles of our literature review, 20 articles address the usage of machine learning (ML) or artificial intelligence (AI) in the context of PGHD. With those technologies on the rise in recent years and the interdisciplinary nature of the topic, the call for this new role can improve the patient-clinician interaction. This call for new roles in healthcare is backed by the fact that in order to successfully integrate PGHD into clinical workflows, additional steps in clinical work itself are required. When introducing PGHD into the clinical ecosystem, data work becomes necessary which leads to translational work (Islind et al. 2019; Lindroth et al. 2018). To decrease the burden clinicians face with this additional data work, we can only support this call for new technically oriented roles in healthcare that create an interface between the technical and the medical side of the healthcare system.

Conclusion

The aim of this literature research was to give an insight into the literature on the topic of PGHD from an IS perspective in order to uncover relevant research gaps. For this reason, we analyzed 131 articles on PGHD in this literature review and analyzed those by means of three research questions. To answer the first research question, we presented different types of PGHD collection methods that produce different kinds of data for a multitude of use cases. The state-of-the-art methods include the usage of hardware like smartwatches, smart sensors and a multitude of combinations of passive and active collection methods. To give insights into the second research question we illustrated how the integration of PGHD into clinical workflows still needs to be improved and standardized to be able to become a state-of-the-art widely used method of treatment in healthcare. To address the third research question, we showed that the introduction of PGHD can cause a shift in patient-clinician interaction before, during and after consultation. The most important finding for this research question is that the introduction of PGHD in patient clinician interaction changes the expectations of patients the demands made on physicians. We identified several research gaps from an IS perspective that need to be addressed in the future. We think it is important to address problems in all three literature streams we discussed in this literature review. Most prominent research gaps are the further inclusion of PGHD in EHR, research on how to improve shared decision-making environments in clinical consultation based on PGHD and the further improvement of PGHD collection methods to increase data quality and trustworthiness. While there remains considerable skepticism regarding the quality of PGHD for clinical use (Karkar 2018), we conclude - based on our results from this literature review - that the introduction of PGHD in healthcare systems is an important step towards further digitalization of healthcare through improved disease prevention, diagnosis and treatment. Due to the presented declining numbers in articles on PGHD since 2018 (Figure 2) and the presented significance of the topic, we call for more research on PGHD.

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