Barriers and Enablers in Integrating Patient-Generated Health Data for Shared Decision-Making Between Healthcare Professionals and Patients: A Scoping Review

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Abstract

Background: Advancements in technologies and increased adoption of wearables and smartphones by individuals have led to an abundance of patient-generated healthcare data. These data, when used effectively, could help to further augment the process of shared decision-making to enable patient-centred care. However, the possible utilization of patient-generated (health) data (PGHD) introduces complexities and challenges which warrant considering both health care professional and patient perspectives.

Objective: Summarize the relevant works in the past 10 years from the perspectives of the key stakeholders – healthcare professionals (HCPs) and patients (PATs) - on potential barriers and enablers to the integration of PGHD for shared decision-making. By looking at both perspectives, we are able to identify the key challenges and opportunities with PGHD throughout the patient's journey.

Methods: Electronic searches were done 3 databases – PubMed, ACM Digital Library and IEEE. Enablers and barriers mentioned by the stakeholders in included papers were extracted. Thematic analysis was performed using a qualitative analysis software, MaxQDA. The six-stage workflow model initially proposed by West at al was used as a reference for deductive coding. Subsequently, considering barriers and enablers faced by both the HCPs and PATs uncovered various tensions and alignments of perspectives which could be addressed in future work and can inform concepts, designs and development in the area of PGHD for shared decision-making.

Results: Fifty-three publications were included in the scoping review. Six main overarching themes for barriers and enablers were identified: 1) Patient-Provider Relationship, 2) Patient Characteristics, 3) Organizational Factors, 4) Medical Ethics and Law, 5) Data-driven workflow and 6) Design and Technology. The six-stage workflow was further expanded based on the new findings.to include four additional stages which include contextual considerations outside of traditional clinical environments. In addition to partially corroborating previously established barriers in the six-stage workflow model, several new barriers and enablers were identified throughout all stages. This model helps to further align needs of HCPs and PATs beyond the clinical setting and could benefit system designers who plan to integrate DHTs involving PGHD for shared decision making.

Conclusions: This scoping review demonstrates that there are several factors to consider for effectively integrating PGHD in health-related shared decision-making. Notably, such factors extend outside the boundaries of traditional clinical settings. Although there is agreement between HCPs and PATs on certain factors, there are also tensions to be addressed. Our findings suggest that apart from lifting the barriers to the integration of PGHD, there can be a role for digital health technologies in mediating alignment between HCPs and PATs on effectively using PGHD for SDM.

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Keywords: Patient-generated health data, patient-generated data, Scoping Review, Data Integration, Shared decision-making, digital health technologies, digital health interventions, wearables, mHealth.

Introduction

The challenges of an ageing population and a chronically ill society have led to increase demands and stress on healthcare systems. Digital health technologies (DHTs) are seen as an enabler to solving such challenges. However, DHTs and consumer healthcare technologies are still facing hurdles in entering the integrated clinical market due to several factors such as infrastructure, technical, training, legal and ethics related barriers [1]. DHTs are identified as enablers towards personalized healthcare and a key application area would be the use of patient-generated health data (PGHD).

The quantified-self movement led by *Quantified-Selfers* who track many kinds of data about themselves [2,3] followed by the mass market adoption of self-tracking technologies, coupled with advancements in mobile sensing technologies have led to an increase in PATs bringing their health data to clinical consultations. PGHD or patient-generated data (PGD), refers to data created, recorded, or gathered by PATs (or by family members or other caregivers) to help address their health concerns [4]. The integration of PGHD has been known to bring about benefits such as 1) *better contextualisation of symptoms* [12], 2) *better clinical decision-making* [5], and 3) *personalised and participatory care* [6,7]. Motivated by the vision that PGHD are believed to help clinicians "*fill in the gaps*" [8] and unlock their potential, national frameworks have also been developed to guide their integration and governance. The European Health Data Space (EHDS), Digital Health Applications (DIGA), and United Kingdom's Personalised Health and Care 2020 framework are frameworks or legislations that can arguably support the use, governance and transmission of PGHD by enabling patient-centric interoperability and fostering linked digital health technology uptake.

Overall, PGHD has the potential to play a key role in digitalisation of healthcare. However, there remain several challenges which lie in the path towards the adoption of PGHD as a foundation for enabling novel and additional insights and applications in clinical practice. Unlike traditional clinical data, which is typically produced through the actions of health care professionals in closely controlled clinical conditions, PGHD are typically gathered throughout situated daily living under strongly varying and individual circumstances. This poses challenges for the interpretation and reliability of PGHD, but also opens opportunities in the form of "objective data windows" into daily living that would otherwise not be available. In addition, many people are nowadays using consumer health-oriented apps and devices (e.g. wearables) and the measures and outcomes reported by these tools will in any case enter the spoken and unspoken information flow around personal health that HCPs and PATs have to navigate in face-to-face settings. Akin to medical and health information being available through internet search [9], this is likely to impact medical examination and shared decision-making.

Making health and care increasingly patient-centric and assuring that PATs feel heard and empowered is an essential goal in many national and international healthcare strategies (e.g. [10–13]). Shared decision-making can be a key enabler of patient-centred care and also help with fostering adherence and self-determined as well as pro-active approaches to health and care. PGHD is particularly relevant in SDM as it empowers PATs to proactively manage their health. It also benefits HCPs by providing a comprehensive view of a patient's health status, capturing insights beyond the clinical setting. By integrating PGHD into SDM, HCPs can better understand patient's preferences, goals and daily experiences, leading to more personalized and patient-centred treatment plans. Moreover, PGHD encourages PATs to engage in self-monitoring and self-care, fostering a sense of ownership and responsibility in their health journey. This collaborative approach, facilitated by PGHD, can enhance the quality of SDM and improve health outcomes. Given the vital role PGHD in improving SDM and empowering PATs in proactively managing their health, it is essential to understand the perspectives of PATs and HCPs on how it can be integrated into care pathways.

Over the past years, several works explored challenges and enablers of integrating PGHD into healthcare context from the perspectives of HCPs and PATs. We perform a comprehensive scoping review aimed at elucidating both the challenges and opportunities in integrating patient-generated health data (PGHD) into shared decision-making (SDM) processes, with a specific focus on the perspectives of both HCPs and PATs.

The scoping review used the methodology formulated by MDJ et al. [14] to investigate the research question (RQ):

RQ1. *What barriers and enablers exist amongst critical stakeholders - HCPs and PATs - to using PGHD to inform shared decision-making?*

This review is useful for system designers and researchers who develop and enhance digital health interventions and technologies which generate PGHD (cf. 10-stage workflow model in).

Methods

This scoping review is reported following the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (*PRISMA-ScR)* [46]. The scoping review approach was chosen over a systematic review process [15] to determine coverage of literature on the topic of PGHD and to identify key factors influencing the integration of PGHD into clinical pathways.

Search Strategy

After looking at prior works in this area and having a consultation amongst the co-authors, we narrowed down to ACM DL, PubMed, and IEEE databases, which cover research in both technical and medical fields. The search was conducted in March 2023.

Several keywords were initially selected after considering highly visible related works in the area. Thereafter, the first and second authors discussed common themes to narrow down to the keywords in a scheme that can be summarized as follows:

1. patient generated data *OR* patient generated health data *OR* [...]
   AND
2. patient-reported outcomes *OR* self-tracking *OR* digital health
   AND
3. shared decision-making *OR* [...]
   AND
4. enablers *OR* barriers OR perspectives OR [...]

Since the terminologies patient generated data and patient-generated health data have been used in prior works, both keywords were included in the search query. Other related keywords, indicated as “ [...] “- were included in the entire search query which can be found in the Appendix.

Inclusion and Exclusion Criteria

The aim of applying inclusion criteria (*IC*s) and exclusion criteria (*EC*s) is to extract only publications relevant to the objective of this SLR. We used the following set of inclusion criteria (ICs):

IC1. Articles published in English at a conference venue or peer-reviewed journal.
IC2. Articles related to non-invasive wearables that generated PGHD (e.g., smartwatch, blood pressure monitor, etc.)
IC3. Studies which involved either HCPs or PATs or both.
IC4. Studies that explicitly mention shared decision-making in person or remotely, mediated via technology, or have elements of SDM.

IC5. The type of self-tracking could either be patient/participant-initiated or clinician-initiated.
EC1. Review articles and study protocols.
EC2. Articles referring solely to the personal health record of the patient.
EC3. Articles with implants or wearables which require invasive surgery.

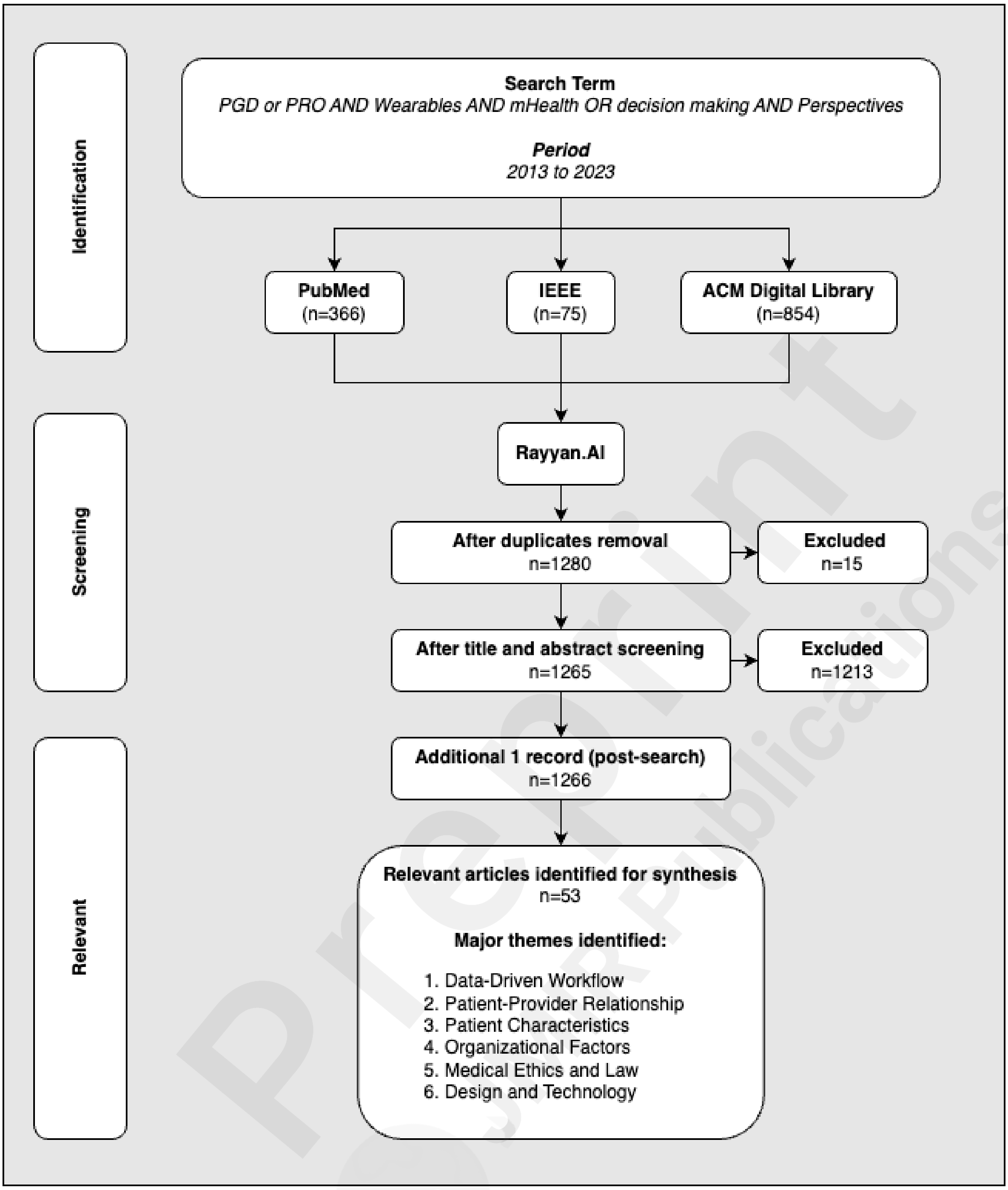
Further details about the inclusion and exclusion criteria can be found in the Appendix.

Results

Screening and data abstraction

Our search in the ACM, PubMed and IEEE digital libraries resulted in 1280 records. The distribution of the results was as follows: ACM: 854, PubMed: 366, IEEE: 75. To streamline the paper selection and review process, the results were exported to an AI-assisted review tool, Rayyan, which aids in duplicate detection and scoring suggestions. After the automatic removal of duplicates by Rayyan and manual removal by the first author, 1280 papers remained. Next, the first and second authors read all titles and abstracts to filter by inclusion/exclusion criteria. Conflicts were resolved during a meeting after considering the research protocol and research question (RQ). One paper was manually added since it was mentioned as an influential related work in four papers [16–19] published in subsequent years. Finally, 53 articles were selected for the full-text review. The first author subsequently performed the data extraction with a validation check-in with the last author after reviewing 25 papers. The flow diagram is provided in Figure 1.

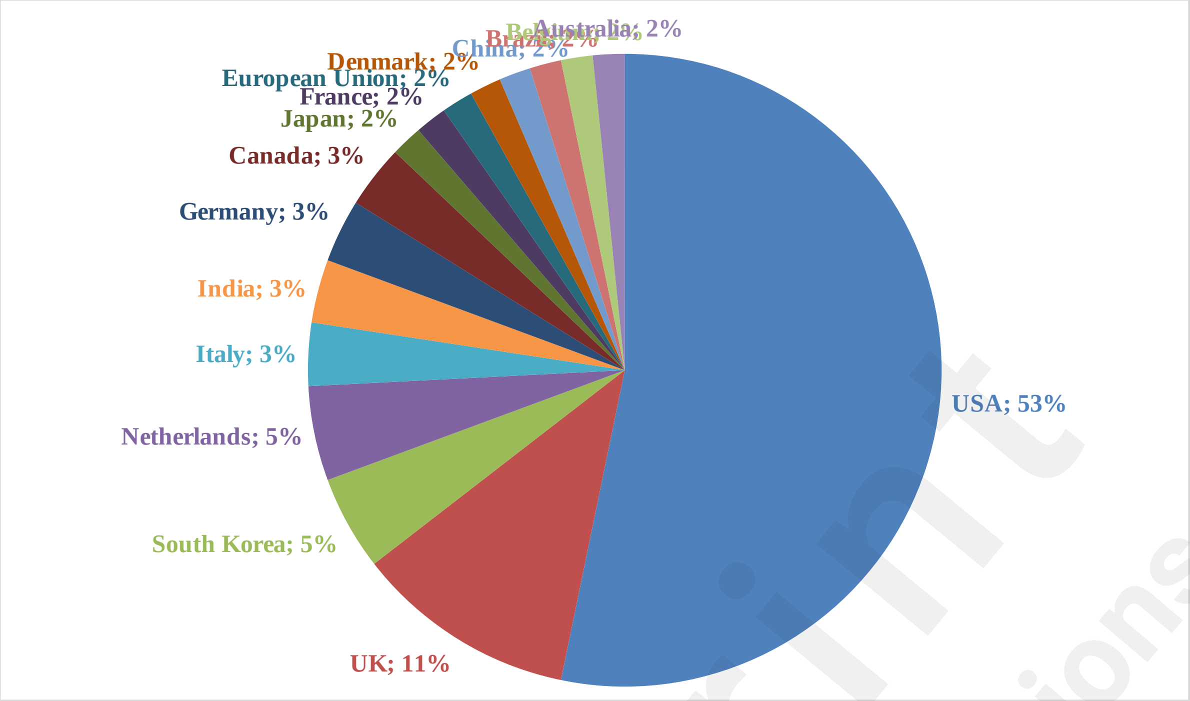
Figure 1 Flow diagram showing data extraction process



The first author familiarized with the data and subsequently generated codes inductively based on RQ1. The first author extracted the data from the papers and imported them into MaxQDA. The data was then analysed for common themes with a methodology adapted based on work for surfacing qualitative insights from primary data, namely thematic analysis by Braun and Clarke. [20]. Subsequently, these themes were further marked as Patient Enabler (*PE*), Patient Barrier (*PB*), Clinician Enabler (*CE*) and Clinician Barrier (*CB*). Clinician was used as a shorthand for a wider understanding of HCP in this step. The detailed subthemes and corresponding categorization can be found in the Appendix – Themes and definition.

The works predominantly originated from English-speaking countries. About 50% (n=3) of were from the US and more than 10% (n=7) from the UK (Figure 2). The final number is higher than 53 as some papers originated from more than one country.

Figure 2 Number of Papers by Country as per listed affiliation



The number of papers published annually has steadily climbed and peaked in 2021. The drop in 2022 could be due to the COVID-19 pandemic, which resulted in a decline in in-person consultations (Figure 3). Furthermore, since the search was conducted in the first quarter of 2023, this resulted in a low count. Most number of papers were about non-communicable diseases and chronic conditions. Only one paper included perspectives of PATs with communicable diseases [21].

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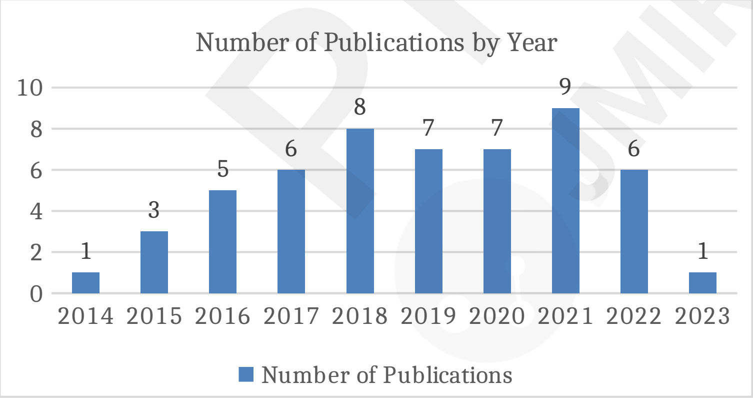
Figure 3 Number of Publications per year (March 2013 - March 2023)



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Factors affecting the integration of Patient-Generated Data for Shared Decision Making

In this section, we present the findings related to our guiding research question:

RQ1. *What barriers and enablers exist amongst critical stakeholders - HCPs and PATs - to using PGHD to inform shared decision-making?*

The analysis identified several enablers and barriers related to the following six themes as established in the analysis:

(1) *Patient-provider relationship (PPR)***,** which refers to the interaction between HCPs and PATs and several factors which affect this interaction, such as trust, expectations over data use etc. (2) *Patient characteristics* were mainly attributed to factors influencing patient's behaviours and habits tracking or the effects of tracking. (3) *Organizational factors* were related to processes within healthcare systems that could be improved or existing barriers preventing PGHD from integrating effectively into their workflow. (4) *Medical ethics and law* refer to ethical and legal considerations such as patient autonomy, the use of PGHD for insurance purposes and the questionable value of PGHD for clinical decisions. (5) *Data-driven workflow* related factors are broadly associated with characteristics, processes and tools related to data, such as integration, standardisation, relevance trustworthiness etc. Finally, (6) *Design and Technology* refers to the technical implementation of tools that generate or utilise PGHD and the consideration of human factors in the design process of such tools.

The tree map diagrams (cf. Enablers in Figure 4 and Barriers in Figure 5) shows the hierarchical breakdown of themes and sub-themes based on the number of occurrences throughout the fifty-three papers selected for the review.

Figure 4 Distribution of Patient and HCP enablers in a hierarchical view

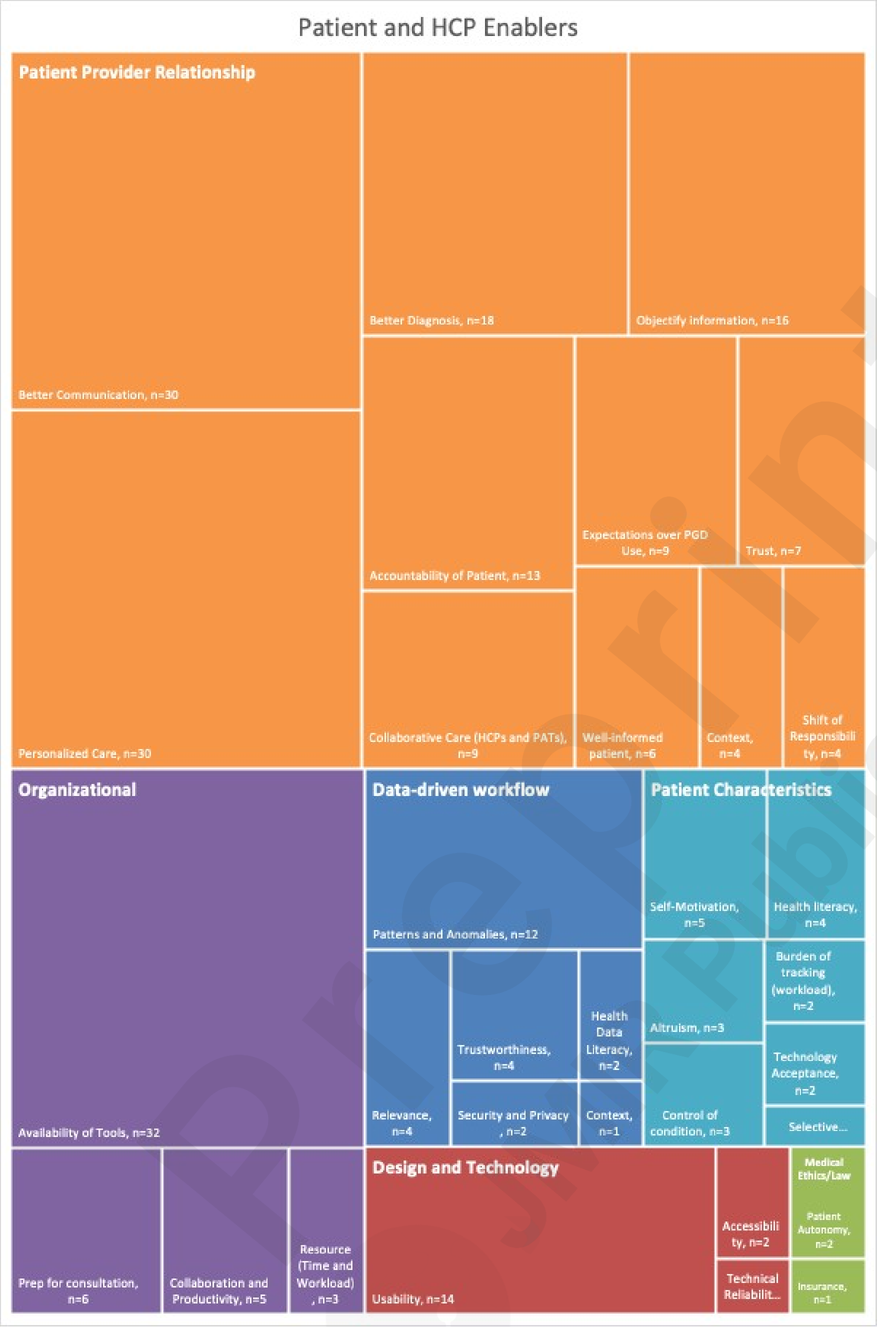
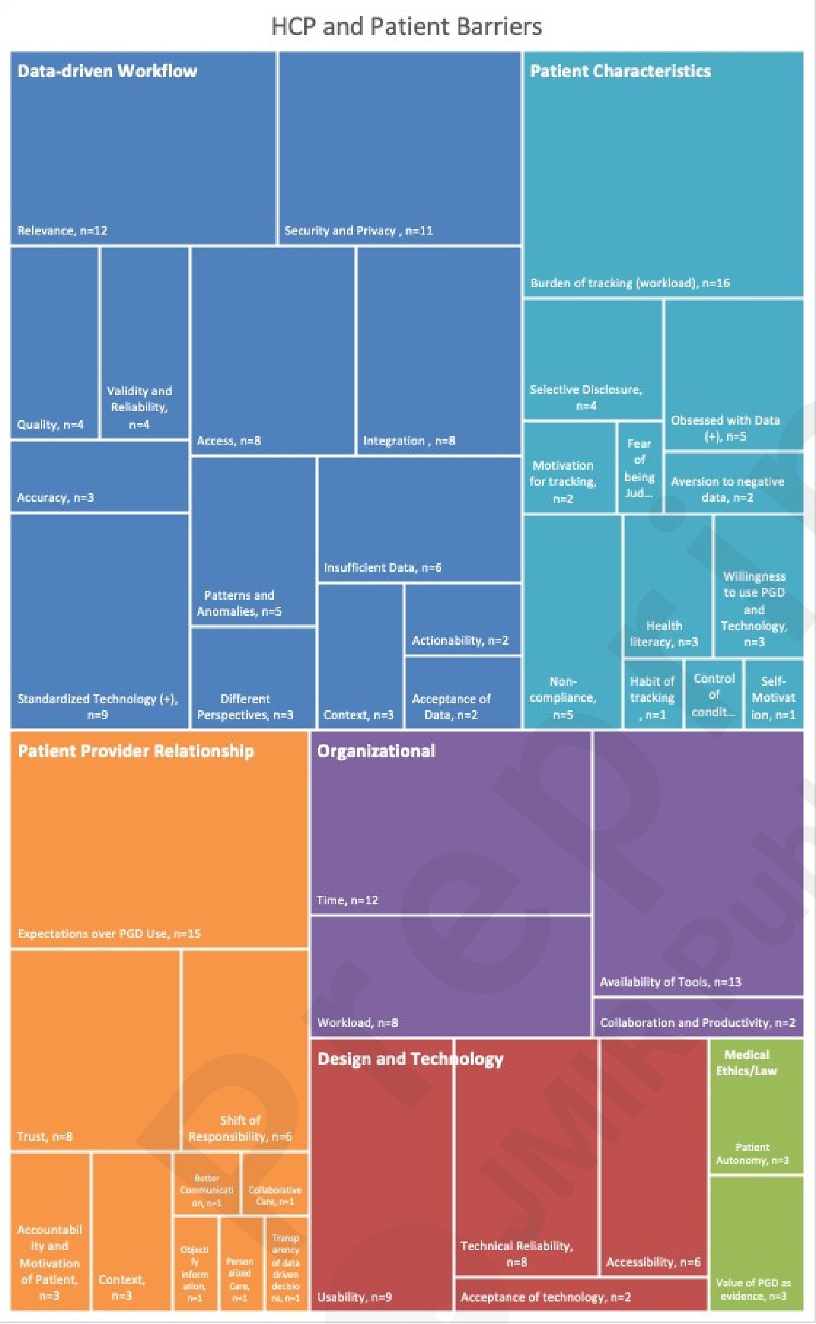


Figure 5 Distribution of Patient and HCP barriers in a hierarchical view



The most significant enabler (Figure 4) for PGHD is how it could promote *Patient-provider relationship*, especially concerning improving communication, allowing for patient-centred care, and providing HCPs with a better picture of the PATs. Aspirations followed this in terms of having mechanisms which enable the making of health data and having data-driven workflows throughout the clinical setting.

Amongst barriers (Figure 5), *Data-driven workflow* (such as lack of standards, poor integration, and lack of access to data) has emerged as the most significant, followed by organisational factors (such as unavailability of tools and lack of time) and *patient characteristics* (such as selective disclosure of data and increased burden of tracking).

In the subsequent sections, we will delve deeper into the specific factors:

Patient-provider relationship (PPR)

PPR is mainly seen as an enabler for the integration of PGHD. The critical factors include the ability to offer *personalised care, facilitate communication* between PATs and HCPs, and improve *diagnosis*. E.g.: *"both healthcare providers and PATs use data to approach the unknown, whether they use it to identify the possible causes of infertility, to identify the fertile window, to decide on potential treatments, or to choose follow-up treatments. [18]* PGHD is also seen as an aid in building *trust* by *objectifying* subjective information: *The physiotherapists found that the information provided by FitViz helped them in conducting "patient–driven" consultations* [22].

While PATs are often enthusiastic about sharing the data with HCPs, "*Patients also wanted to use their data to get recognition for their efforts and to show their doctor they take their health plan seriously*" [23] HCPs are concerned about a *shift of responsibility* as they might be more accountable for the data shared by the patients: "*Clinicians were concerned that by having continuous access to patient data, they would become responsible for monitoring that data for concerning changes that may be indicative of a mental health crisis, such as a manic episode or a suicide attempt*" [24] and feel an obligation to interpret and explain the data: *"Simply" receiving patient-generated data around daily symptoms created a feeling of an "obligation to act" for the clinicians"* [25]. Moreover, with the capability of remote monitoring, PATs "*want to have the ability for their physician to conduct remote monitoring to verify the treatment plan is working and to pick up early warning signs of relapse or deterioration*"[26].

Patient characteristics

HCPs, in general, are worried about the *(unintended) consequences* of PATs tracking and bringing their PGHD to consultations. They feel that an increased emotional attachment of PATs to their PGHD could lead to *depression* and *anxiety*. For example, therapists highlight that "*depression could be a potential side effect of tracking*"[27].Furthermore, PATs could also "*overreact to [negative] data.*" [28] Both HCPs and PATs have concerns about the effort required for tracking and feel that tracking could increase PATs' *burden*. For instance, in a study by Anker et al. [21], a diabetes patient who had given up self-monitoring of blood glucose said, "*It's too cumbersome for me*".

In addition, PAT motivations on sharing data with HCPs are not always clear due to *selective disclosure* As "*patient makes the decision about what kind of data the clinician can see, clinicians [were] uncomfortable*" [24] with such data unless they had the entire dataset.

HCPs are concerned about the *"increased transparency via PGHD and how it could lead to noncompliance"* [29].

Although most feedback was negative, clinicians feel that having access to data could allow PATs to better engage with their data through *introspection* and *motivate* them to self-treat their conditions. PATs feel more self-aware of their condition and data helps them see their habits [23]. Furthermore, PATs also believed that sharing their data could benefit future research for treating PATs with similar conditions: "*They hoped their Fitbit data would benefit future veterans*" [30].

Data-driven workflow

The data-driven workflow theme comprised several enablers and barriers. Within the theme, there are several factors considered as enablers, among which the generation of data, data actionability, and having access to standardised tools integrated well into the clinical workflow.

From the HCP's perspective, data *sensemaking* is a key enabler. For example, HCPs feel that "*When patients struggled to identify triggers, visualisations of quantitative analyses could help patients and providers understand underlying nutrient-symptom relationships"* [29]. PATs also feel that *sensemaking* was a key enabler for effectively utilising PGHD and that connecting with the data allowed for a better understanding of their health conditions and improved self-care. For example, in a study of diet monitoring, "*HCPs and participants were able to [make sense of their data to] identify eating patterns or potential triggers and used Foodprint as a structuring artifact to discuss actionable next steps*" [17]. However, in a study with diabetes PATs and providers, *"commercially available visualizations that are built using clinical guidelines were useful for providers but not for patients"* [31]. HCPs want *standardised* tools to interact with data and better understand the patient's condition. For instance, HCPs stress the importance of a "*uniform clinician interface that integrates patient-generated data from various individual tools, supporting the findings in previous studies*" [32] and take appropriate action, leading to better *data actionability*. *Contextual information* – how and when the data was collected - is also mentioned as a key to data actionability. Access to the data's context could allow for the discovery of "*possible confounds including emotional and physical health, hydration, and exercise* " [33].

Integration could enable HCPs to *access* and review data before consultations. In one of the studies, "*geriatricians preferred to review the data before the consultation, and then implement a new part of their care plan based on the data*" [34].

There are also several barriers identified, such as a need for more digital literacy in working with health data for the trustworthiness of data.

The introduction of tools and effective adoption and acceptance meant that HCPs must have the necessary *literacy* skillsets for interacting with data. Some "*[HCPs] doubt their ability to advise on tracking; many providers doubt patient ability to review tracking data.*"[11] .Some HCPs also highlight the need for better *data integration* with existing EHR and EMR systems. For example, Zhu et al. [36] found that as "*commercial sleep tracking technology did not support data exporting or sharing, many clinicians continued to use paper sleep diary*."

However, with more data, there are also remarks about the data's *quantity*, *quality*, and *reliability*, which could, in turn, affect its *trustworthiness*. When "*different patients use different apps, it [became] difficult for health care providers to interpret the data and assess the reliability of each app*" [37].

Regarding the amount of data, some HCPs feedback about receiving or reviewing data relevant to the consultation, given that unnecessary data could result in ineffective decision-making. From the patient's perspective, there is also a lack of awareness about what to track. As a result, *"many wanted to track more data than may be feasible"* and wanted to have *"smart defaults for how to track because they did not know what would reasonably balance burden and usefulness"* [45].

Organizational Factors

Organizational factors mainly encompass factors about a healthcare organisation such as a hospital. The primary barrier is HCPs' lack of time –"*The cardiologists in our sample already encounter problems with data overload in their daily practice*" [38] and the need for more time and effort to review patient data. HCP share that "*patient-provided data sources will add layers of data assessment to practice, and questioned whether this information may adversely affect efficient workflow*" [39].

HCPs need more support, tools, and incentives from upper management to integrate PGHD into clinical care practices. HCPs feel that although activity monitoring tools could help to streamline means of collecting data, "*current activity monitoring tools are insufficient to address program specific prehabilitation assessment needs; to exacerbate this challenge, stakeholder tailored tools do not currently exist*" [40]. Regarding clinical workflow, HCPs feel that PGHD could be beneficial in allowing them to review PATs' conduct to *prepare for consultations* beforehand, leading to better consultations. "*Nearly all providers agreed that the best time to receive the patient-generated health report was immediately before a scheduled clinic visit*" [41]. This in turn, leads to better consultations: "*Pre-visit notes helped health experts focus on participant goals and questions when reviewing food photos*" [17].

Medical Ethics/Legal Aspects

Medical Ethics and Legal Aspects refer to the responsibility of HCPs, ethics, and legal aspects of data**.** HCPs are worried about **regulations** such as HIPAA obstructing the introduction of PGHD into their care practices. Furthermore, **autonomy** is a factor for concern amongst HCPs and PATs. For example, some "*older adults perceived that monitoring that monitoring PGHD increased the transparency of their (lack of) engagement in healthy behaviours" and "perceived [it] as a threat to autonomy*" [29].

Finally, the *unproven value of PGHD* in healthcare - "*lack of evidence for use*" [5] and how such data is used to diagnose or treat conditions was a limiting factor in its adoption. A HCP felt frustrated rearranging the PGHD data and structure it as evidence within their clinical framework [39]. Within the broader theme of ethics and legalities, one HCP mentions how PGHD could benefit insurance concerning a patient's recovery*: "I think it's also good to show insurance kinda, hey, we are making changes, you know, getting them better in this aspect" [27].*

Design and Technology

Both HCPs and PATs highlight that well-implemented technologies with *good usability* can be a driver for adoption and sustained use. For example, amongst PATs, learnability and ease of use – sub qualities of usability – are favourable for PATs in two studies: "*GeniAuti made their recording process easier in everyday life"* [42] and "*ease-of-use of DiaFocus and found it easy to use and easy to learn to use* " [43].

For HCPs, the *usability* of their tools is a key factor for adopting PGHD and missing features such as "*inability to sort the data*" [44] and added additional *time*. HCPs are also concerned about the *reliability* of the applications and the technologies that the PATs adopted, especially when PATs might use a myriad of them based on their preferences. On the other hand, when a "*When hospitals offer the same app that has been clinically validated to all patients, health care providers can become, over time, knowledgeable about a [it]*" [37].

Overall, both stakeholders believe that technologies should be designed to be *accessible* so that population groups such as older adults could adopt these technologies. "*Clinicians also alluded to old age as a potential challenge as the older generation is not as fluent with mHealth, wearable technology, and other devices that collect PGHD*" [29]. In a particular study, a participant's medical condition - Rheumatoid Arthritis - caused issues with their participation due to the tool's accessibility [45].

Beyond clinical settings

Our analysis includes a wide range of barriers and enablers which can be arranged across a patient's journey to provide logical flow and structure. In doing so, we extend and augment West et al.'s [3] work - A *six-stage workflow model aligning patient and clinician objectives* - beyond a clinical setting (cf.). Our updated workflow identifies *four new stages* encapsulated within the pre- and post-consultation phases. It also emphasises the dyadic relationship between the HCPs and PATs and the various factors influencing the integration of PGHD along the patient journey. It starts from the data collection (Stage 1) point till a clinical action is taken (Stage 10) and repeats (especially for PATs with chronic or multiple conditions).

The following subsections describe the newly added steps in further detail:

(1) Collect Data

This stage is a crucial point where PATs initiate the tracking of their health data. . In some cases, they might be embarking on this activity on their own or through social influence; on the other hand, it could have been due to instructions from their HCP, e.g., when treating medical conditions over the long term. However, it is also worth noting that the monitoring process requires additional effort – although there are methods for passive collection, e.g. through wearable or stationary sensing devices, these do require some effort to setup and maintain. As such, both active (e.g. through occasional questionnaires or more frequent Ecologic Momentary Assessment) as well as passive sensing introduces an additional *burden* to PATs – on top of managing their medical condition.

[PAT] "mentioned that daily measurements were too burdensome or medicalizing, especially when they perceived their symptoms or blood pressure to be stable" [46].

(2) Reflect on Data

In the *reflection stage*, PATs can interact with the data they collected through the various sensemaking mechanisms available. This could be presented as data summaries, PDF reports, graphs of different formats. However, at this stage, there are both facilitators and barriers. By accessing such data, PATs could reflect on their physiological data such as stress levels, weight, etc and information such as physical activity trends.

"[P]atients looked to their data for self-awareness of their current lifestyle and described its value in terms of helping them see their habits" [23].

This could allow them to be well-informed about themselves before consultations. However, if *“veterans do not understand or trust the data, it could be difficult for them to be motivated to use it”* [30].
There were also incidents in specific medical conditions - e.g. in mental health - where having access to such data could reinforce negative views of their condition and agitate symptoms [47] or demotivate PATs.

“Many unengaged patients reported being easily discouraged by their [arterial fibrillation] AF recurrence, which they said caused them to self-monitor less“ [48].

(3) Integrate Data

The next stage entails the import of data into a clinical setting. In the *integrate data* stage, the patient attempts to “upload” their data into clinical systems, or the clinician could manually associate them with their EHR systems (a common need to store the foundations for decision-making). However, at this stage, clinicians faced trouble importing such data due to incompatibilities or insufficient interfaces to their systems. In a study, although “*patients used mobile apps for their sleep diary, clinicians who received this data had to manually input each data point*” [36] due to limitations in data sharing functionalities. There were issues about poor interoperability of self-tracking technologies – primarily due to the non-standardization of devices or technologies – which prevented seamless integration into EHR systems.

Notably, current generation digital technologies for supporting sensemaking from PGHD cannot easily scale to novel data types, handle incomplete or incongruent data, or integrate multimodal PGHD streams.

(10) Take Action

Finally, in the *taking action* stage, after a consultation with an HCP, the presence of data could allow PATs to be more accountable for self-treating their conditions based on decisions made during the consultations. However, in some cases, there was a concern about the clinician’s ability to monitor patient’s condition remotely or with more granular details; this could invade patient’s privacy and threaten their *autonomy* [29]. In addition to this, although HCPs could give recommendations to PATs on what tools to use to control their condition, they might not necessarily comply with it:

“Providers sometimes recommended tracking tools to patients for clinical diagnosis and management. However, patients do not always follow those recommendations. [13].

Discussion

The democratization of health-related self-tracking and as a consumer trend following the early adopter quantified self-movement have led to individuals bringing PGHD to consultations – commonly referred to as patient-initiated tracking [49]. PGHD is believed to bring about several benefits, such as more objectively reflecting the situated health status of PATs and opening up possibilities for increasing motivation for PATs, allowing for self-reflection over recovery progress and contributing towards predictive, preventive personalized and participatory (P4) medicine [50]; however, with a lack of transparent processes, standardised tools and communications over how data should be presented during consultations, individuals bringing their PGHD to consultations would currently most likely add additional workload for HCPs, by providing irrelevant and non-standard data and expecting interpretation. Furthermore, such individuals might have varying motivations for getting their PGHD and might selectively disclose data. This calls for improved integration workflows, which could help transfer data into hospital systems, sensemaking tools - e.g. using data visualisation techniques – for better utilization of relevant data-derived information during SDM. This emphasises the need to adopt a systemic lens on the issue of integrating PGHD into clinical practice, motivating our augmented 10 stage workflow model (Figure 6) . This model includes pre- and post-consultation phases, as well as corroborated formerly identified barriers and enablers (bold) and newly identified ones (italics).

Towards enabling integration of PGHD for shared decision-making

Overall, the scoping review outcomes emphasise a need to adopt a systemic lens on the issue of integrating PGHD into clinical practice. In a clinical context, healthcare professionals may already be facing increased risk of burnout due to poor technology integration [51], and given the potential benefits but also burden PGHD brings, there is a need to prioritise how data-related tools can be better integrated. On a higher level, there needs to be organisational support in creating policies and processes to support the use of PGHD and creating data-driven workflows that seamlessly integrate such data into clinical practices. However, we identified challenges in a clinical setting involving how PATs collect data and the specific barriers that enable them to manage data when moving into the clinical context.

Work on aligning and interactively navigating priorities between HCP and PAT appears clearly implicated. Tensions could arise from patient preferences or the subjectivity of data due to the emotional connectivity of the data conflicting with HCP adopting a very objective view of data with their medical background - typically due to medical ethics. By juxtaposing the needs and priorities of both stakeholders, we discussed the alignments and tensions between them. Our work also identifies design opportunities for system designers to consider addressing and balancing the stakeholder's priorities adequately by pro-actively building on enablers and avoiding or decisively tackling barriers.

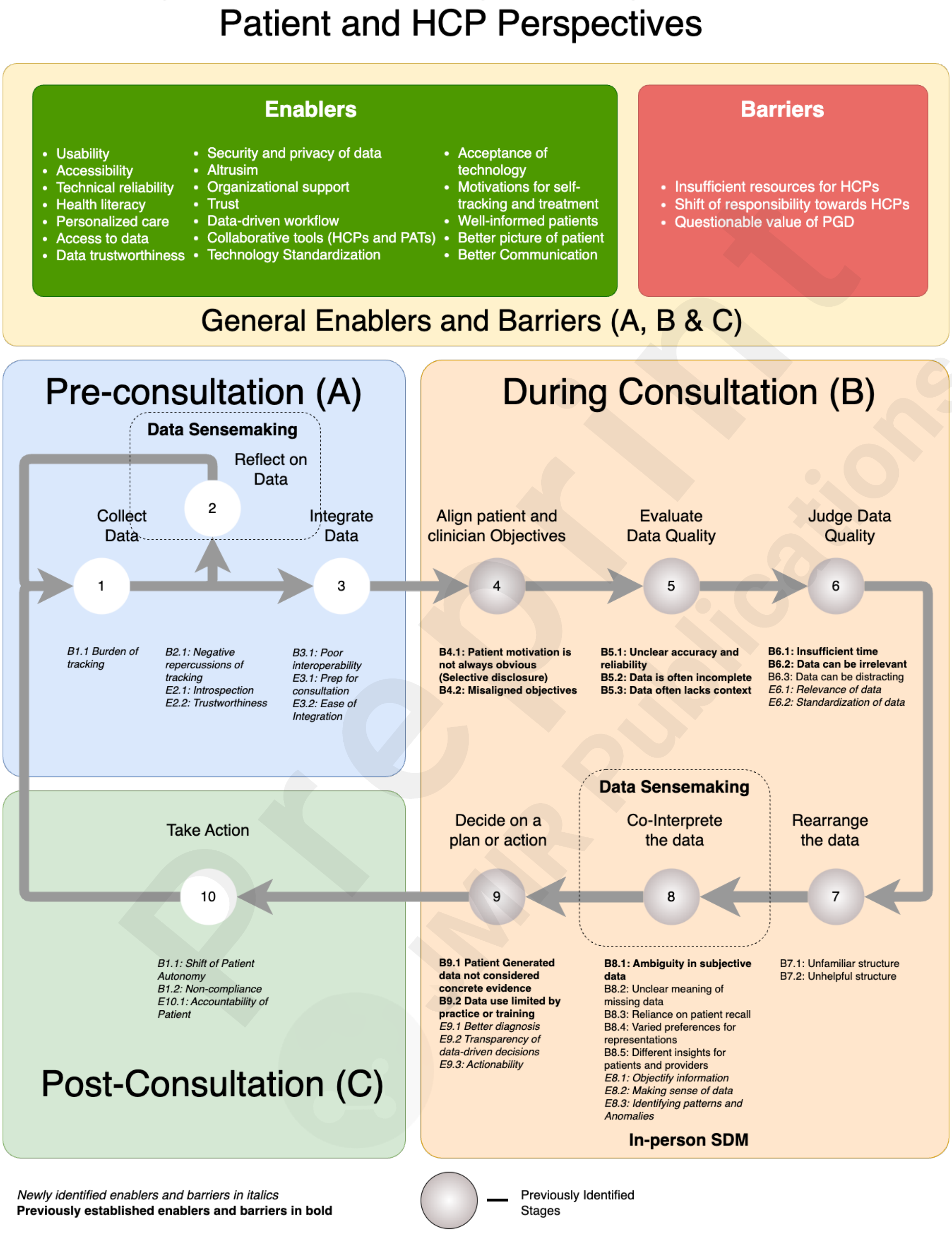
Addressing barriers

Table 1 contains strategies for addressing barriers along the stages in the 10 -stage workflow model.

Table 1 Barriers and mitigation strategies

Stages	**Barriers**	**Strategies**
	Pre consultation	
Collect Data (1)	1. Burden of tracking	Utilize passive tracking as much as possible and recommend only tracking that is necessary for consultations.
Reflect on Data (2)	1. Negative Repercussions of tracking	Educate PATs on possible negative impacts of data and offer adequate resources to obtain support on data sensemaking.
Integrate Data (3)	1. Poor data integration	Standardize interfaces and data export formats amongst commercial devices and applications for better integration into EHR systems
	Post consultation	
Take Action (10)	1. Shift of patient autonomy 2. Non-compliance	Ensure that patient preferences on how their data is viewed and accessed are respected and communicated with them transparently. Educate PATs on the benefits of adherence.
	All stages	
-	Overburdened clinicians	All stages: Implement data sense-making support in-line with clinical workflows. Consider shifting to partially automated sensemaking steps that already occur before consultation and could help
-	Lack of time for HCPs	Introduce tools to improve the operational efficiency of clinical workflows
-	Questionable value of PGHD	Conduct empirical research on PGHDs and how they improve patient-centred care.

Figure 6 The adapted 10-stage workflow for using patient-generated data



Addressing Tensions and Alignments

The following sections will detail tensions as well as aligned perspectives between HCP and PAT. Excerpts from relevant papers are presented below each point:

Tension 1. PATs need clarification or were unaware of the *relevance of data* and needed more *health literacy*. This results in (*time-limited*) HCPs facing an overload of (unnecessary) data.

[There is] a need to negotiate with patients when determining which data elements to collect, set patients' expectations for communication about PGHD, and let patients know that they would not be contacted if everything was normal. [44]

Older adults and clinicians perceived that the lack of clinical knowledge by patients leads to a collection of irrelevant PGHD and decreases the usefulness of the information. [29]

Tension 2. PATs, at times, have a subjective and emotional connection with their data and were hoping for detailed explanations of the data they brought for consultations. HCPs, however, intend to view the data objectively while making clinical decisions. This can result in mismatched expectations over collected data by PATs and sometimes misunderstandings over how HCPs made clinical decisions using the data, which results in ineffective consultations.

Patients also expected providers to engage with the data and provide a personalised treatment plan. [23]

The conflicting views often led to disagreement between the caregivers' and experts' interpretations of the children's challenging behaviours. [42]

Tension 3. PATs feel that increased monitoring and visibility of PGHD could lead to disruption of their autonomy and loss of privacy, however, HCPs feel that having (access to) more (readily available) data could allow for better health support.

Participants were concerned about talking to clinicians they needed to become more familiar with and about the privacy of their PGD. [52]

Tension 4. HCPs desire a *complete picture of the PATs (to facilitate decision-making)* but at the same time feel challenged by *increased workload* due to the increased data and insufficient time to handle them.

If patients share the collected data with their doctor, the interpretation of the data and appropriate response becomes the doctor's response. [38]

Provide the Context, Longer View, and Whole Picture. [53]

Tension 5. PATs have issues trusting the HCP's ability to interpret and review data. Furthermore, HCPs themselves had self-doubts about their capabilities.

These barriers include a lack of time to review detailed records, questions about providers' expertise, and scepticism about additional benefits of reviewing data. [35]

The visualizations also caused some unease for [participants], who mentioned feeling "embarrassed" or "anxious" about giving the impression that they lacked necessary knowledge to explain the visualizations. [33]

Tension 6. PATs and HCPs have varied preferences on which type of problem to focus on and how they wanted the data to be represented.

> *"Patients and providers differ on the type of problem to focus on."*
> *"Data gives different insights to patients and providers."*
> *"Patients and providers use different representations of data to identify problems."*
> [31]

Table 2 details the tensions faced between HCPs and PATs while interacting with PGHD and how they can be resolved.

Table 2 Tensions and alignment strategies

#	Tension	Alignment Strategies
1	PATs' lack awareness about what data to bring vs time-starved HCPs	Improve *health (data) literacy* of PATs, *align expectations* or establish *standards* over what data is needed for the consultation and for SDM thereby engendering mutual *trust*.
2	PATs' subjectivity vs HCPs objectivity	HCPs should set *expectations* over how PGHD would be used for SDM and provide explanation on how they influenced the SDM process.
3	HCP's want to have easy access to PAT data but PATs want to have autonomy and privacy	PATs and HCPs should set boundaries over how and when HCPs track PGHD to maintain *patient autonomy*. Appropriate *privacy* mechanisms could be designed for dynamic configuration of consent.
4	HCPs want to have a complete picture of PATs but have limited time	Equipping HCPs with the *necessary tools* such as Clinical Decision support and AI-assisted systems could help augment HCPs with PGHD interaction.
5	Perceived lack of HCP capabilities in interaction with data affected trust.	Improve HCP's *data literacy* capabilities and assure PATs about their abilities to make data-driven decisions.
6	Differing perspectives and approaches that PATs and HCPs have when interacting with health data for diagnosis	Tools should *promote mutual understanding between both PATs and HCPs* and support problem identification, preferably in an automated manner [31]

Limitations

The findings were based on the papers derived from three major databases, and other published/non-peer-reviewed works could be available in other repositories. Furthermore, there could be subjectivity in the interpretation of the findings. Since HCPs and PATs unequally contributed to the findings, the perspectives should be explicitly assessed in empirical work and in a balanced manner. However, these preliminary findings give readers and designers a sense of factors to consider when integrating PGHD into digital health technologies and the wider healthcare systems.

Conclusions

PGHD has a great potential to enhance patient-centred care and lead towards P4 medicine. However, its widespread integration in clinical settings still needs to be improved. By reviewing works from the past ten years and incorporating both patient and clinician perspectives, we identified several enablers and barriers across six key themes: 1) *Patient-Provider Relationship*, 2) *Patient Characteristics*, 3) *Organisational Factors*, 4) *Medical*

Ethics and Law, 5) *Data* and 6) *Design and Technology*. We build on the previous model by West et al. [54] by adding four new stages beyond the clinical setting, including , “reflect on data”, “integrate data”, and “take action”. Our 10-stage workflow model of aligning patient and clinician objectives in integrating PGHD implies several challenges to be tackled and can form the foundation for deriving design implications around tensions and agreements between HCPs and PATs along data-driven patient journeys. We also include according recommendations and design suggestions . By addressing challenges introduced by PGHD, the communications and SDM could be more efficient for both parties, leading to better patient-centred care and life-accompanying personalized health.

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Conflicts of Interest

None declared.

Abbreviations

PGHD: Patient generated health data.
PAT: Patient
HCP: Health care professionals
RQ: Research question
EHDS: European Health Data Space
DIGA: Digital Health Applications
UK: United Kingdom
USA: United States of America

Multimedia Appendix 1

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Appendix – Search Query

ACM Digital Library

"PGD" OR "PGHD" OR "Patient-Generated Data" OR "Patient Generated Data" OR "Patient Generated PGD" OR "Patient-Generated PGD" OR "personal health*" OR "personal informatic*" OR "patient-contributed data" OR "patient contributed data" OR "patient-centered data" OR "patient-centred data" OR "Patient Centered data" OR "Patient Centred data" OR "patient-reported outcomes" OR "patient reported outcomes" AND "self-track*" OR "self track*" OR "body-worn*" OR "body worn*" OR "wearable*" OR "smartphone*" AND "mhealth" OR "telehealth" OR "mobile health" OR "health" OR "medic*" OR "digital-health" OR "digital health" OR "shared decision-making" OR "shared decision making" OR "clinical decision-making" OR "clinical decision making"OR "SDM" OR "patient-provider collaboration" OR "patient provider collaboration" OR "doctor-patient communication" OR "doctor patient communication" OR "telerehab" OR "Telerehabilitation" AND"Barriers" OR "hurdles" OR "needs" OR "problems" OR "Facilitators" OR "enablers" OR "Opportunities" OR "Goals" OR "Aspirations" OR "Perspectives" OR "Experiences" OR "Perceive" OR "Experience" OR "Lessons"

PubMed

"PGD" OR "PGHD" OR "Patient-Generated Data" OR "Patient Generated Data" OR "Patient Generated PGD" OR "Patient-Generated PGD" OR "personal health*" OR "personal informatic*" OR "patient-contributed data" OR "patient contributed data" AND "self-track*" OR "patient-contributed data" OR "patient contributed data" OR "patient-centered data" OR "patient-centred data" OR "Patient Centered data" OR "Patient Centred data" OR "patient-reported outcomes" OR "patient reported outcomes" AND "self track*" OR "body-worn*" OR "body worn*" OR "wearable*" OR "smartphone*"AND"mhealth" OR "telehealth" OR "mobile health" OR "health" OR "medic*" OR "digital-health" OR "digital health" OR "shared decision-making" OR "shared decision making" OR "clinical decision-making" OR "clinical decision making"OR "SDM" OR "patient-provider collaboration" OR "patient provider collaboration" OR "doctor-patient communication" OR "doctor patient communication" OR "telerehab" OR "Telerehabilitation"AND"Barriers" OR "hurdles" OR "needs" OR "problems" OR "Facilitators" OR "enablers" OR "Opportunities" OR "Goals" OR "Aspirations" OR "Perspectives" OR "Experiences" OR "Perceive" OR "Experience" OR "Lessons"

IEEE

PGD" OR "PGHD" OR "Patient-Generated Data" OR "Patient Generated Data" OR "Patient Generated PGD" OR "Patient-Generated PGD" OR "personal health*" OR "personal informatic*" OR "patient-contributed data" OR "patient contributed data" OR "patient-contributed data" OR "patient contributed data" OR "patient-centered data" OR "patient-centred data" OR "Patient Centered data" OR "Patient Centred data" OR "patient-reported outcomes" OR "patient reported outcomes" AND "self-track*" OR "self track*" OR "body-worn*" OR "body worn*" OR "wearable*" OR "smartphone*"AND"mhealth" OR "telehealth" OR "mobile health" OR "health" OR "medic*" OR "digital-health" OR "digital health" OR "shared decision-making" OR "shared decision making" OR "clinical decision-making" OR "clinical decision making"OR "SDM" OR "patient-provider collaboration" OR "patient provider collaboration" OR "doctor-patient communication" OR "doctor patient communication" OR "telerehab" OR "Telerehabilitation"AND"Barriers" OR "hurdles" OR "needs" OR "problems" OR "Facilitators" OR "enablers" OR "Opportunities" OR "Goals" OR "Aspirations" OR "Perspectives" OR "Experiences" OR "Perceive" OR "Experience" OR "Lessons"

Appendix – Themes and definition

Themes	Code	Explanation
Design & Technology	Usability	A system which is easy to learn, easy to use and offers good user experience
	Accessibility	Considering needs of a diverse population group, including excluded populations.
	Technical Reliability	Robustness of technology which prevents it from errors or failures which could influence stability and reliability of device
Patient Provider Relationship	Trust	Patient's trust in HCPs and Vice Versa
	Better communication	Improved communication between HCP and Patients
	Collaborative care	Interactions between Patients or with doctors to improve health condition.
	Better picture of patients	Allows HCPs to have a better view of a patient's condition with availability of additional data.
	Well-informed patient	Patients who are aware about their healthcare conditions prior to consultations
	Expectations over PGD Use	Agreement between HCP and Patient how PGD is tracked and used during consultations
	Shift of Responsibility	Increase in responsibility of doctors because of integrating and interpreting PGD
	Better Diagnosis	Allows HCPs to offer better diagnoses because of the increased information about the patient's condition
	Accountability and Motivation of Patient	Patients have a better sense of accountability because of having access to PGD
	Transparency of data driven decisions.	Patients are interested in knowing how doctors made the decision using PGD

	Objectify information	PGD helps to objectify subjective data provided by patients
	Personalized Care	HCPs can offer tailored care based on the PGD
Patient Characteristics	Health literacy	Patients' ability to find, understand, and use information make health-related decisions.
	Self-motivation	Patient's motivation to self-treat by monitoring themselves
	Burden of tracking (workload)	Increased workload for patients from tracking
	Negative repercussions (of tracking)	Anxiety, Depression and Obsession with Data
	Altruism	Patient's willingness to share their PGD to improve research and innovation in healthcare sector
	Selective Disclosure	Patient's privacy concerns about their behaviour or conditions which prevents them from revealing information about themselves.
	Non-compliance	Patient's being unwilling to use the technology because of increased transparency and accountability
	Acceptance of technology	Patient's willingness to adopt technologies for tracking and technology acceptance.
	Introspectivity	Patient's ability to engage with their PGD to improve self-treatment of their conditions
Organizational	Resource	HCPs not having enough time to look through the data or having too much workload
	Collaboration and Productivity	Allows for data-driven collaboration between multiple stakeholders: doctors, patients, and caregivers.
	Process, Tools and Policies	HCPs share about factors related to workplace policies
	Prep for consultation	Allows HCPs to have access to the PGD before the consultation to prepare beforehand.
Data	Health Data Literacy	HCPs and Patients being equipped with the relevant knowledge and technical skillsets to make sense of the PGD.
	Security and Privacy	Patients' and HCP's concerns about safekeeping of data.

	Context	Having information about the context in which the PGD was collected.
	Sensemaking	HCPs and Patients being able to making sense of the PGD.
	Trustworthiness	Trust and reliability of the PGD which was collected.
	Relevance	Presenting only relevant PGD data during consultations without overwhelming HCPs with unnecessary data.
	Actionability	HCPs being able to create adequate treatment plans using the data.
	Standardization	Having a standardized data format which can integrate into clinical systems.
	Integration	The ability to integrate data with EHR and EMR systems.
	Access	HCPs having easy and quick access to PGD.
	Insufficient Data	Incomplete data for HCPs to make decisions.
Medical Ethics/Law	Patient Autonomy	Allowing patients to making decisions on their own without pressure from HCPs.
	PGD's Value as evidence	Reliability of PGD in clinical context for decision making.
	Insurance	Use of PGD for insurance sector.

APPENDIX – Main Characteristics of included papers

Paper ID (First name, Year)	Paper Title	Publication Venue (Name of conference or journal)	Country of Origin	Sample Size	Medical Condition (Acute/ Chronic)	Technology
JAKOB 2023 [43]	DiaFocus: A Personal Health Technology for Adaptive Assessment in Long-Term Management of Type 2 Diabetes	ACM Transactions on Computing for Healthcare	Denmark	Patients (n=12)	T2D (Chronic)	Smartphone App, Diafocus Mobile sensing platform, Accu-chek guide BGM.
Nick E.J. 2022 [26]	Personalized vascular healthcare: insights from a large international survey	European Heart Journal	USA, UK, China, Japan, France, Germany, India, Italy, and Brazil	Patients (n=961) HCPs (n=345)	Vascular Diseases (Chronic)	Not specified/N.A.
Karine 2022 [33]	Digital Self-monitoring of Multiple Sclerosis: Interview Study With Dutch Health Care Providers on the Expected New Configuration of Roles and Responsibilities	JMIR Mhealth Uhealth.	Netherlands	HCPs (n=28)	Multiple Sclerosis (Chronic)	Smartphone self-monitoring application - MS sherpa.
Ayanna 2022 [55]	'Are They Doing Better In The Clinic Or At Home?': Understanding Clinicians' Needs When Visualizing Wearable Sensor Data Used In Remote Gait Assessments For People With Multiple Sclerosis	CHI	USA	HCPs (n=10)	Multiple Sclerosis (Chronic)	Dashboard for Clinicians.
Chi Young 2022 [56]	Patients Waiting for Cues: Information Asymmetries and Challenges in Sharing	CSCW	USA	Patients (n=57)	General	Not specified/N.A.

Paper ID (First name, Year)	Paper Title	Publication Venue (Name of conference or journal)	Country of Origin	Sample Size	Medical Condition (Acute/ Chronic)	Technology
	Patient-Generated Data in the Clinic					
Eunkyung 2022 [42]	GeniAuti: Toward Data-Driven Interventions to Challenging Behaviors of Autistic Children through Caregivers' Tracking	CSCW	South Korea	Parents and Children with Autism (n=38) HCP (n=3) Caregivers (n=6)	Autism (Chronic)	GeniAuti - a system that assists caregivers in systematically tracking their children's challenging behaviors and their response strategies for data-driven discussion with clinical experts.
Tessa 2022 [57]	Snoozy: A Chatbot-Based Sleep Diary for Children Aged Eight to Twelve	IDC	Netherlands	Clinicians (n=6) Parents (n=6) Children (n=6)	Insomnia (Chronic)	Chatbot as a sleep diary.
Katie 2021 [58]	Remote Measurement in Rheumatoid Arthritis: Qualitative Analysis of Patient Perspectives	JMIR	UK	Patients (n=9)	Rheumatoid Arthritis (Chronic)	Not specified/N.A.
Vaughn 2021 [59]	Seriously ill pediatric patient, parent, and clinician perspectives on visualizing symptom data	Journal of the American Medical Informatics Association	USA	Children (n=14) Parents (n=14) HCP (n=30)	Sickle Cell Disease, Cancer, and Bone Marrow Transplant (Chronic)	Hardware (Apple Watch) and Mobile App + Software(Visualization evaluation).
Jutta 2021 [45]	Mobile App-based documentation of patient-reported outcomes — 3-months results from a proof-of-concept study on modern rheumatology patient management	Journal on RA	Germany	Patients (n=111)	Rheumatoid Arthritis (Chronic)	Mobile Application.

Paper ID (First name, Year)	Paper Title	Publication Venue (Name of conference or journal)	Country of Origin	Sample Size	Medical Condition (Acute/ Chronic)	Technology
Jay 2021 [60]	Data Contribution Summaries for Patient Engagement in Multi-Device Health Monitoring Research	Ubicomp	United Kingdom and European Union	Patients (n=24) HCPs (n=9)	Huntington's disease, Parkinson's disease, inflammatory bowel disease (Chronic)	Mobile application with multiple sensing devices.
Ben 2021 [29]	Clinicians and Older Adults' Perceptions of the Utility of Patient-Generated Health Data in Caring for Older Adults: Exploratory Mixed Methods Study	JMIR	Canada	Older Adults (n=5) HCPs (n=4)	General	Not specified/N.A.
Hoefer 2021 [24]	The Multiplicative Patient and the Clinical Workflow: Clinician Perspectives on Social Interfaces for Self-Tracking and Managing Bipolar Disorder	DIS	USA	HCPs (n=17)	Bipolar Disorder (Chronic)	Mobile Application.
Gupta 2021 [22]	Oh, I Didn't Do a Good Job: How Objective Data Affects Physiotherapist-Patient Conversations for Arthritis Patients	Pervasive Health	Canada	HCPs (n=7)	Arthritis (Chronic)	Web Application (FitViz).
Costa 2021 [18]	Using Data to Approach the Unknown: Patients' and Healthcare Providers? Data Practices in Fertility Challenges	CSCW	USA	Patients (n=14) HCPs (n=5)	Infertility (Chronic)	Paper, websites, digital spreadsheets, fertility apps, wearables, or a combination of these.

Paper ID (First name, Year)	Paper Title	Publication Venue (Name of conference or journal)	Country of Origin	Sample Size	Medical Condition (Acute/ Chronic)	Technology
Caldeira 2021 [16]	Towards Supporting Data-Driven Practices in Stroke Telerehabilitation Technology	CSCW	USA	Patients (n=10) HCPs (n=4)	Stroke (Chronic)	Game based Tele rehabilitation.
Haining 2020 [40]	Prehabilitation: Care Challenges and Technological Opportunities	CHI	USA	HCPs (n=12)	Cancer, Facial nerve Palsy (Acute), Elderly, ENT, Knee Replacement (Acute and Chronic)	Varied Sensing and Medical Devices.
Wu 2020 [61]	Clinician Perspectives and Design Implications in Using Patient-Generated Health Data to Improve Mental Health Practices: Mixed Methods Study	JMIR	USA	HCPs (n=12)	Mental Health (Chronic)	Mobile Applications
Luo 2020 [52]	Interrelationships Between Patients' Data Tracking Practices, Data Sharing Practices, and Health Literacy: Onsite Survey Study	JMIR	USA	Patients (n=109)	General	Not specified/N.A.
Danielle 2020 [5]	mHealth and patient generated health data: stakeholder perspectives on opportunities and barriers for transforming healthcare	mHealth	USA	Healthcare Consumers (n=21) HCP (n=15) Healthcare Administrators (n=5)	General	Not specified/N.A.
Jongsma 2020 [46]	User Experiences With and Recommendations for Mobile Health Technology for Hypertensive Disorders	JMIR Mhealth Uhealth	Netherlands	Patients (n=63)	Pregnancy (Acute)	-Automated blood pressure monitor with Bluetooth connection -Smartphone app for

Paper ID (First name, Year)	Paper Title	Publication Venue (Name of conference or journal)	Country of Origin	Sample Size	Medical Condition (Acute/ Chronic)	Technology
	of Pregnancy: Mixed Methods Study					iOS users and a web-based portal for Android users.
Bhat 2020 [28]	Sociocultural Dimensions of Tracking Health and Taking Care	CSCW	India	Patients (n=18) HCPs (n=8)	Cardiovascular Disease (Chronic)	Smartphone App
Alpert 2020 [34]	Secondary care provider attitudes towards patient generated health data from smartwatches	npj digital medicine	USA	HCPs (n=12)	General	Hardware and Software.
Tendedez 2019 [25]	The Issue with That Sort of Data?': Clinicians' Accountability Concerns Around COPD Self-Monitoring Tools	CSCW	UK	HCPs (n=4)	Chronic Obstructive Pulmonary Disease (Chronic)	Software.
Schroeder 2019 [19]	Examining Opportunities for Goal-Directed Self-Tracking to Support Chronic Condition Management	ACM IMWUT	USA	Patients (n= 14) HCPs (n=5)	Migraine (Chronic)	Software.
Ng, Ada 2019 [47]	Provider Perspectives on Integrating Sensor-Captured Patient-Generated Data in Mental Health Care	CSCW	USA	HCPs (n=17)	PTSD (Chronic)	Hardware - Fitbit
Iott 2019 [62]	Clinician Perspectives on the User Experience, Configuration, and Scope of Use of a Patient Reported Outcomes (PRO) Dashboard	PervasiveHealth	USA	HCPs (n=25)	Cancer (Chronic)	Software - PRO Data Dashboard tool
Hue 2019 [63]	Exploring the Future Role of Self-Tracking Data in the Rheumatology Clinic	Healthcare of the Future	UK	Patients (n=28)	Ankylosing spondylitis (Chronic)	Not specified/N.A.
Chung 2019	Identifying and Planning for	ACM IMWUT	USA	Healthy participants	Irritable Bowel	Software –

Paper ID (First name, Year)	Paper Title	Publication Venue (Name of conference or journal)	Country of Origin	Sample Size	Medical Condition (Acute/ Chronic)	Technology
[17]	Individualized Change: Patient-Provider Collaboration Using Lightweight Food Diaries in Healthy Eating and Irritable Bowel Syndrome			(n=17) Patients (n=16) HCP(n=15)	Syndrome (Chronic)	(1) a mobile app supporting in -the-moment, low-burden food capture (2) a web app presenting relationships between food and health goals, (3) a pre-visit note asking participant summary about their data and their goals and expectations for the visit.
Abdolkhani 2019 [64]	Patient-generated health data management and quality challenges in remote patient monitoring	JAMIA Open	Australia	HCPs (n=9) Health information professionals (n=4) Remote patient monitoring solution providers (n=7)	Diabetes, Cardiac Arrhythmia, Sleep Disorder (Chronic)	**Diabetes**: Continuous glucose monitoring (CGM) devices and insulin pumps; consumer wearables were various types of fitness trackers **Cardiac arrhythmia**: an event monitoring wearable Sleep disorder: the medical wearable was a sleep monitoring/ activity watch.
Erin 2018 [65]	Technologized Talk: Wearable Technologies, Patient Agency, and Medical Communication in Healthcare Settings	International Journal of Sociotechnology and Knowledge Development	USA	Patients (n=84)	General Health management (Chronic and Acute)	Not specified.

Paper ID (First name, Year)	**Paper Title**	**Publication Venue (Name of conference or journal)**	**Country of Origin**	**Sample Size**	**Medical Condition (Acute/ Chronic)**	**Technology**
West 2018 [54]	Common Barriers to the Use of Patient-Generated Data Across Clinical Settings	CHI	UK	HCPs (n=13)	General Health management (Chronic and Acute)	Not specified.
Tendedez 2018 [66]	Scoping the Design Space for Data Supported Decision Making Tools in Respiratory Care: Needs, Barriers and Future Aspirations	PervasiveHealth	UK	HCPs (n=4) Health information professionals (n=6)	Chronic Obstructive Pulmonary Disease (Chronic)	Not specified.
Reading 2018 [48]	Factors influencing sustained engagement with ECG self-monitoring: perspectives from patients and health care providers	Journal of Applied clinical informatics	USA	Patients (n=13) Research coordinators (n=2)	Atrial fibrillation (chronic)	Mobile electrocardiogram (ECG) monitor and smartphone application.
Piras 2018 [67]	Clinical self-tracking and monitoring technologies: negotiations in the ICT mediated patient–provider relationship	HEALTH SOCIOLOGY REVIEW journal	Italy	Parents (n=8) Children/Adolescents (n=4) Patients(Adults) (n=17) HCPs (n=3) Health information professionals (n=3)	T1D (Chronic)	Mobile application and Support Platform.
Mishra 2018 [30]	Veterans’ Perspectives on Fitbit Use in Treatment for Post-Traumatic Stress Disorder:An Interview Study	JMIR MENTAL HEALTH	USA	Patients (n=13)	Mental Health (Chronic) PTSD	Fitbit software and Charge HR.
Mishra 2018 [68]	Supporting Collaborative Health Tracking in the Hospital:Patients’ Perspectives	CHI	USA	Patients and caregivers (n=30)	General	PGHD tracking platform
Gabriels	Exploring entertainment	JMIR	Belgium	HCPs (n=12)	General	N.A.

Paper ID (First name, Year)	Paper Title	Publication Venue (Name of conference or journal)	Country of Origin	Sample Size	Medical Condition (Acute/ Chronic)	Technology
2018 [38]	medicine and professionalization of self-care: interview study among doctors on the potential effects of digital self-tracking					
Zhu 2017 [36]	Making Space for the Quality Care: Opportunities for Technology in Cognitive Behavioral Therapy for Insomnia	CHI	USA	Patients (n=17) HCPs (n=11)	Insomnia (Chronic)	N.A.
Schroeder 2017 [33]	Supporting Patient-Provider Collaboration to Identify Individual Triggers Using Food and Symptom Journals	CSCW	USA	Patients (n=10) HCPs (n=10)	IBS(Chronic)	N.A.
Raj 2017 [31]	Understanding Individual and Collaborative Problem-Solving with Patient-Generated Data: Challenges and Opportunities	CSCW	USA	Interviews = Patients and Caregivers (n=5), Caregiver (n=1), Patients (n=8), Clinicians (n=2) Focus group = Clinicians (n=4) Observations = Clinic sessions (n=5), Phone call sessions (n=6)	Diabetes (Chronic)	Continuous Glucose Monitor, Insulin Pump
Malu 2017 [27]	Sharing automatically tracked activity data: implications for therapists and people with mobility impairments	PervasiveHealth	USA	Patients (n=10) HCPs (n=10)	Mobility Impairment (Chronic)	Software and Hardware.
Kim 2017	Prescribing 10,000 Steps	CHI	South Korea	HCPs (n=4)	General Health	Not specified/N.A.

Paper ID (First name, Year)	Paper Title	Publication Venue (Name of conference or journal)	Country of Origin	Sample Size	Medical Condition (Acute/ Chronic)	Technology
[32]	Like Aspirin: Designing a Novel Interface for Data-Driven Medical Consultations			Health information professionals (n=5) Others (n=11)	(Acute and Chronic)	
Kelley 2017 [69]	Self-Tracking for Mental Wellness: Understanding Expert Perspectives and Student Experiences	CHI	USA	Student Health Professionals (n=14) Students (n=297)	Mental Health (Long Term)	Not specified/N.A.
Zhu 2016 [4]	Sharing Patient-Generated Data in Clinical Practices: An Interview Study	AMIA	USA	Patients (n=12) HCPs (n=9)	General	Not specified/N.A.
West 2016 [39]	The Quantified Patient in the Doctor's Office: Challenges & Opportunities	CHI	USA	HCPs (n=10)	General	Excel Sheet iPhone App
Kim 2016 [70]	"My Doctor is Keeping an Eye on Me!": Exploring the Clinical Applicability of a Mobile Food Logger	CHI	Korea	Patients (n=20) HCPs (n=11)	Lifestyle Diseases (Chronic)	Software - mfood logging application.
Cohen 2016 [44]	Integrating Patient-Generated Health Data Into Clinical Care Settings or Clinical Decision-Making: Lessons Learned From Project HealthDesign	JMIR	USA	Study Team members (n=13) HCPs (n=12)	Diverse Health issues: Cognitive Decline, Moderate to severe asthma, adolescent behavioural health, Crohn disease, health issues with premature infants	Software.
Chung 2016 [23]	Boundary Negotiating Artifacts in Personal Informatics: Patient-Provider Collaboration with	CSCW	USA	Patients (n=229) HCPs (n=21)	IBS, Obesity, (Chronic)	Not specified/N.A.

Paper ID (First name, Year)	Paper Title	Publication Venue (Name of conference or journal)	Country of Origin	Sample Size	Medical Condition (Acute/ Chronic)	Technology
	Patient-Generated Data					
Ryokai 2015 [53]	Communicating and interpreting wearable sensor data with health coaches	PervasiveHealth	USA	Participants (n=5) HCPs (n=4)	Health Coaching	Hardware and Software.
Chung 2015 [35]	More Than Telemonitoring: Health Provider Use and Nonuse of Life-Log Data in Irritable Bowel Syndrome and Weight Management	JMIR	USA	HCP (n=21)	IBS, Weight Management (Chronic)	Software Dashboard (Fitbit, Gut Guru, Health Report (Conceptual app to allow patients track symptoms between visits).
Ancker 2015 [21]	“You Get Reminded You’re a Sick Person”: Personal Data Tracking and Patients With Multiple Chronic Conditions	JMIR	USA	Patients (n=22) HCPs (n=7)	MCC (including diabetes, HIV, heart disease, depression, and many others)	Hardware - Blood Glucose and pressure monitor Software - medication, weight, food.
Nundy 2014 [41]	Using Patient-Generated Health Data From Mobile Technologies for Diabetes Self-Management Support	Journal of Diabetes Science and Technology	USA	HCPs (n=12)	Diabetes (Chronic)	Software (SMS and CareSmarts Dashboard

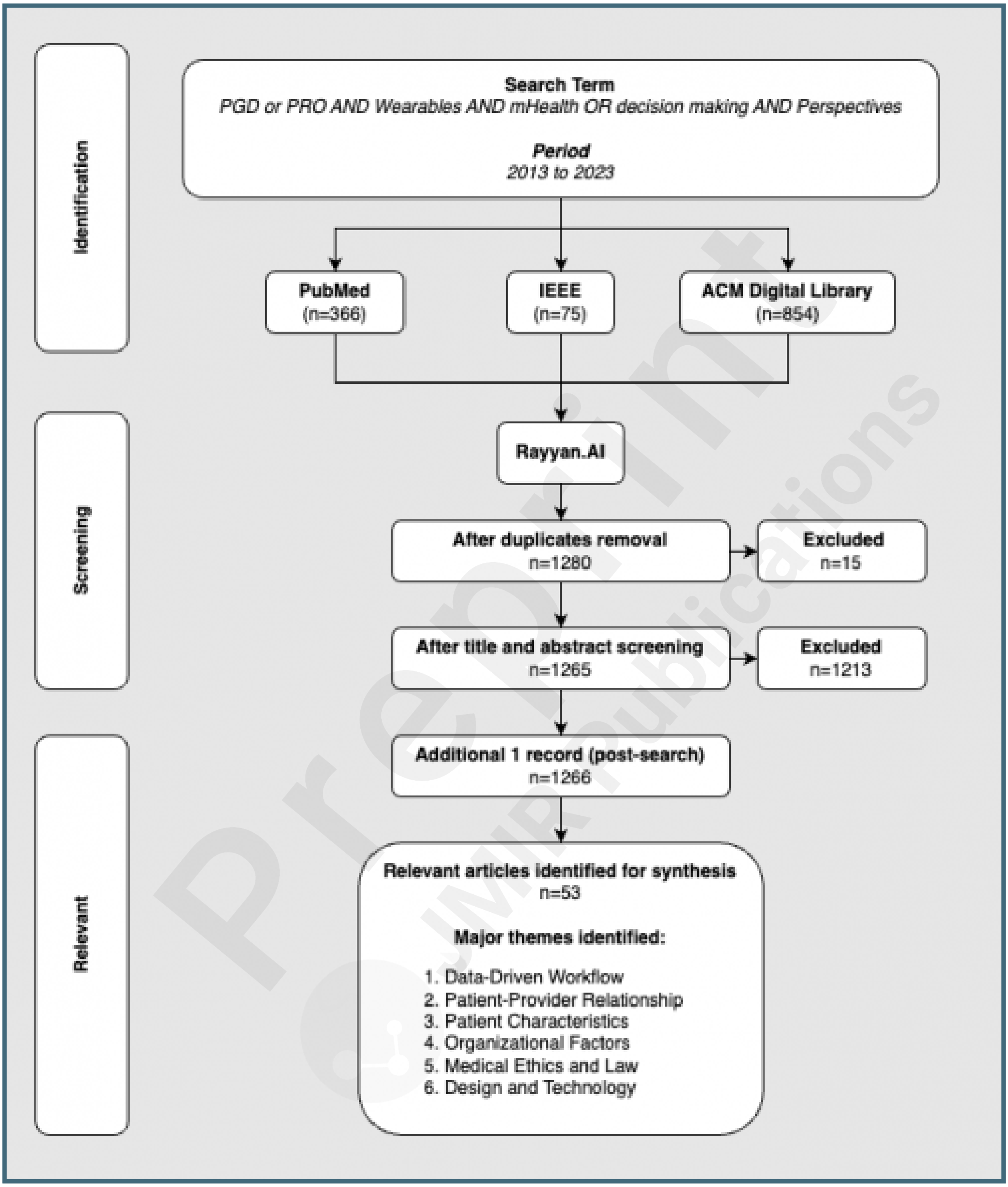
Appendix – Inclusion and Exclusion Criteria

Time Frame	2013-2023
Language	English
Type of Technology	Wearables (smartwatch, blood pressure monitor, etc.), Smart health device (weighing scale, etc.), PC and laptop computer, Smartphone, Smartphone applications (mood tracker, diet tracker, period tracker, etc.) excluding implants
Stakeholders	Patient and HCP
Publication Type	Peer-reviewed journal or conference article excluding meta-research (i.e., review papers) and study protocols
Initiation of Self-Tracking	Initiated by participants or patients or by clinicians
Focus of Study	Patient generated health data integration for shared decision-making during in-person consultations or remote monitoring.

Supplementary Files

Figures

Flow diagram showing data extraction process.



The adapted 10-stage workflow for using patient-generated data.