An Exploratory Study on the Utility of Patient-Generated Health Data as a Tool for Health Care Professionals in Multiple Sclerosis Care

Sharon Guardado[1]   Vasiliki Mylonopoulou[2]   Octavio Rivera-Romero[3,4,5]   Nadine Patt[6]   Jens Bansi[6]
Guido Giunti[1,7,8,9]

[1] Empirical Software Engineering (M3S) Research Unit, Faculty of Information Technology and Electrical Engineering, University of Oulu, Oulu, Finland
[2] Division of Human-Computer Interaction, Department Of Applied Information Technology, University of Gothenburg, Gothenburg, Sweden
[3] Department of Electronic Technology, Universidad de Sevilla, Seville, Spain
[4] Instituto de Investigación en Informática, Universidad de Sevilla, Seville, Spain
[5] SABIEN Group, ITACA Institute, Universitat Politécnica de Valéncia, Valencia, Spain

Address for correspondence Sharon Guardado, MSc, Faculty of Information Technology and Electrical Engineering, University of Oulu, Pentti Kaiteran katu 1, 90570 Oulu, Finland (e-mail: sharon.guardadomedina@oulu.fi).

[6] Department of Neurology, Kliniken Valens, Rehabilitationszentrum Valens, Valens, Switzerland
[7] Health Sciences and Technology Unit, Faculty of Medicine, University of Oulu, Finland
[8] Applied Ergonomics and Design, Faculty of Industrial Design Engineering, Delft University of Technology, Delft, The Netherlands
[9] Clinical Medicine Neurology, School of Medicine, Trinity College Dublin, Dublin, Ireland

Methods Inf Med 2023;62:165–173.

Abstract

Background Patient-generated health data (PGHD) are data collected through technologies such as mobile devices and health apps. The integration of PGHD into health care workflows can support the care of chronic conditions such as multiple sclerosis (MS). Patients are often willing to share data with health care professionals (HCPs) in their care team; however, the benefits of PGHD can be limited if HCPs do not find it useful, leading patients to discontinue data tracking and sharing eventually. Therefore, understanding the usefulness of mobile health (mHealth) solutions, which provide PGHD and serve as enablers of the HCPs' involvement in participatory care, could motivate them to continue using these technologies.

Objective The objective of this study is to explore the perceived utility of different types of PGHD from mHealth solutions which could serve as tools for HCPs to support participatory care in MS.

Method A mixed-methods approach was used, combining qualitative research and participatory design. This study includes three sequential phases: data collection, assessment of PGHD utility, and design of data visualizations. In the first phase, 16 HCPs were interviewed. The second and third phases were carried out through participatory workshops, where PGHD types were conceptualized in terms of utility.

Results The study found that HCPs are optimistic about PGHD in MS care. The most useful types of PGHD for HCPs in MS care are patients' habits, lifestyles, and fatigue-inducing activities. Although these subjective data seem more useful for HCPs, it is more challenging to visualize them in a useful and actionable way.

Keywords
► patient-generated health data
► mHealth
► participatory
► informatics
► multiple sclerosis

Conclusion   HCPs are optimistic about mHealth and PGHD as tools to further understand their patients' needs and support care in MS. HCPs from different disciplines have different perceptions of what types of PGHD are useful; however, subjective types of PGHD seem potentially more useful for MS care.

Background

Patient-Generated Health Data

Patient-generated health data (PGHD) are defined as health-related data created, recorded, or gathered by individuals to help address a health concern.[1] They are also known as person-generated health data when they refer to healthy individuals tracking health-related behaviors.[2] While PGHD is distinct from data generated in clinical settings, it cannot be interpreted in isolation and sometimes only gains meaning in conjunction with clinical data.[2] PGHD encompasses diverse datasets derived from digital solutions, including both passive and active sensing methods. Passive sensing involves the use of wearable devices and sensors to collect objectively measurable health data, also known as digital biomarkers.[3,4] Examples of digital biomarkers include body temperature, heart rate, blood pressure, blood glucose, and oxygen saturation.[5] Additionally, mobile technologies enable the collection of subjective data about patients' perception of individual aspects such as mood, symptoms, or pain assessment.[1,3]

PGHD requires patients to self-track, which transforms the typical roles of patients and doctors, empowering patients to be active participants in their health care rather than passive receivers of health care services.[6] Furthermore, active self-tracking with specific goals has been shown to be effective in supporting patients with chronic conditions[7,8] by improving their satisfaction, allowing them to engage in self-management[9,10] and participate in shared decision-making.[6,11] Despite these numerous benefits, the use of PGHD poses several challenges that must be addressed, including data security and privacy and data validity and actionability.[1]

Participatory Health Informatics

Participatory health informatics (PHI) is a multidisciplinary field that leverages information technology to increase individuals' participation in their care. It deals with the resources, devices, and methods required to support the active participation and engagement of the stakeholders.[12] The goals of PHI include maintaining health and well-being, improving the health care system and health outcomes, and achieving life goals, among others.[12] Within PHI's context, mobile health (mHealth) and PGHD can increase the participation of individuals in their care, serving as enablers of different stakeholders' involvement in participatory health processes.[12] Research has shown that patients are willing to share a variety of health information with health care professionals (HCPs)[13] to support long-term management and communicate about diagnosis and treatment-related decision-making.[7,8] However, for clinical purposes, the mere act of collecting and sharing PGHD does not automatically lead to meaningful outcomes unless the data are effectively integrated into the clinical workflow.[7] While HCPs express openness to the use of PGHD,[10] in practice, few are actively using it in their clinical routines.[14] It is known that the HCPs' acceptance of mHealth solutions positively influences their patients' trust in those solutions[8]; therefore, if HCPs are reluctant to utilize PGHD, its anticipated benefits may be limited, with patients' motivation decreased, potentially leading to the discontinuation of tracking and sharing of data.[1,5,15] Most commercially available mHealth solutions are not designed to facilitate data sharing, making collaboration through these tools time-consuming and impractical for many HCPs.[16] As a result, frustration may arise for both patients and HCPs when expectations are not met.[17] Given that the perceived usefulness of technology plays a crucial role in HCPs' acceptance of mHealth solutions,[18,19] improving the usefulness of those solutions could motivate HCPs to use and recommend them.[9]

mHealth in the Care of Multiple Sclerosis

Multiple sclerosis (MS) is a chronic inflammatory and neurodegenerative disease of the central nervous system that represents the most common cause of neurological disability among young adults in the developed world.[20,21] Persons with MS (PwMS) experience a wide range of symptoms that affect mobility and cognitive functions, significantly impacting their quality of life.[20,22,23] Given the complexity of the disease, a multidisciplinary approach is advocated, involving a team of HCPs. Management strategies must be tailored to individual patients, including multidisciplinary assessments, rehabilitation, and appropriate treatment.[24] Guidelines recommend a multidisciplinary therapy approach for the successful management of MS symptoms. However, strong evidence is available only for unimodal interventions, such as physical therapy, exercise, or energy management programs.[25] In the outpatient setting, MS monitoring relies on infrequent assessments (typically once or twice per year), with scarce objective assessments of disease progression[26] and few types of data available to provide personalized health care services, treatments, and cost-effective therapies.[20] Fatigue represents a widespread symptom reported by 90% of PwMS, making it one of the most frequent and disabling symptoms of MS.[27] Previous research has identified that mHealth self-management tools can help PwMS to gain a sense of control over MS[28] and could also lower the costs and burden of travelling to clinic-based assessments, improving the capture of PGHD regarding impairments and functioning of PwMS.[29] For HCPs, PGHD could enhance the long-term management process, improving the understanding of patients' individual needs without negatively

impacting their workload.[30] However, for those benefits to be achieved, HCPs must find the value in using mHealth solutions; therefore, special attention should be devoted to understanding their needs and expectations as stakeholders in the care process of MS.[15]

Objectives

The primary objective of this study is to explore the potential utility of different types of PGHD derived from mHealth solutions that could serve HCPs in the care of chronic conditions such as MS that require highly individualized health care. The exploration process was constructed around the More Stamina app, which is a mobile solution designed to support PwMS with their fatigue; however, the focus of this study is on the perspective of the HCPs as stakeholders in MS care.

A secondary objective of this study was to identify challenges with the proposed exploration process and identify factors that can enhance the process in future studies.

Related Research

Previous research indicates that only approximately 14% of HCPs working in MS care feel they can manage the needs and expectations of their patients.[31] Although some mHealth solutions for MS have emerged to address this need, there is a limited understanding of issues such as how these solutions serve HCPs in their work,[32] how HCPs engage with the datasets produced by them,[33] or how they can enable HCPs' involvement in participatory health.

To address these knowledge gaps, this study focuses on the context of the More Stamina Project, a multidisciplinary collaboration between researchers across the globe and health institutions across Europe. The project aims to develop the More Stamina app while simultaneously exploring how to connect stakeholders, especially HCPs and family members, to improve collaboration and the well-being of PwMS.[34,35] The project follows the patient and public involvement concept, with PwMS representatives actively participating in strategic decision-making, design and development, and providing their expertise.[36] The More Stamina mobile app is a self-management task organization tool designed to help PwMS manage their energy to minimize the impact of fatigue on their daily life. The app learns about the user's habits, tracks activity trends, and provides individualized recommendations accordingly. Additionally, the app can monitor the users' physical activity through smartphone sensors and collects patient-reported outcomes, including the Fatigue Severity Scale and Chalder Fatigue Scale. Users have control over the information they choose to disclose and with whom they share it.[35] The app was designed following a user-centered and participatory design approach through iterative development for continuous improvement. Previous related studies have explored the needs, barriers, and facilitators of mHealth apps for PwMS,[22] conducted a systematic app review of MS digital solutions,[37] conducted initial usability testing of the app,[34] performed a user testing and piloting as part of an ongoing multicenter

study,[35] and carried out the early health technology evaluation utilizing DigiHTA.[38]

Research Methodology

This study comprised three sequential and interrelated phases, with each phase building upon the results of the previous one.[39] An exploratory approach was employed to gain insights from HCPs on the potential utility of participatory health technologies, such as mHealth solutions, in the context of MS care. We followed a mixed-methods methodology, combining qualitative research and participatory design approaches.[40] The phases of the study were (1) data collection, (2) assessment of PGHD utility, and (3) design of data visualizations. The data collection was done through interviews, while the subsequent phases were carried out during a series of participatory workshops. ►Fig. 1 illustrates the flow of the exploratory process.

Data Collection Phase

Qualitative data regarding the use of mHealth solutions and PGHD were gathered from HCPs through individual semi-structured interviews. Purposive sampling was employed to invite experienced HCPs in MS care from both outpatient and inpatient settings in Spain and Switzerland, respectively. A total of 16 HCPs were interviewed. Interviews with the Spanish participants were conducted in their native language, while interviews with Swiss participants were conducted in English, with the assistance of a native German speaker available for translation if needed. Each interview lasted approximately 40 to 45 minutes, was audio-recorded, and subsequently transcribed verbatim. The transcriptions of the Spanish interviews were later translated into English.

The interviewed HCPs represented multiple medical disciplines, including neurology, neuropsychology, psychology, nursing, occupational therapy, physical therapy, and exercise science. Most of the sample was female (15 females and one male), and the mean age was 39.9 years (standard deviation [SD]: 12.6). All interviewees were treating PwMS at the time of the interview, with an average of 12.4 years of experience working in MS care (SD: 10.8). After the completion of the interviews, a thematic analysis was carried out individually by five researchers from the More Stamina project (including S.G., V.M.. and G.G.) using the qualitative analysis software nVivo. The collected data were first analyzed using an open coding process, followed by axial coding to find relationships between the codes. The codes were synthesized and grouped into two main categories of concepts linked to the use of mHealth solutions, each named with a concise statement: *mHealth for patient self-management* and *PGHD for HCPs' use*.

Assessment of PGHD Utility

The second phase of the exploration process entailed further conceptualization of PGHD as a support tool for HCPs in the care of PwMS. Three participatory workshops were conducted with HCPs working in two separate health centers (Spain and Switzerland). All participants had a minimum of 1 year of experience working with PwMS, with over two-
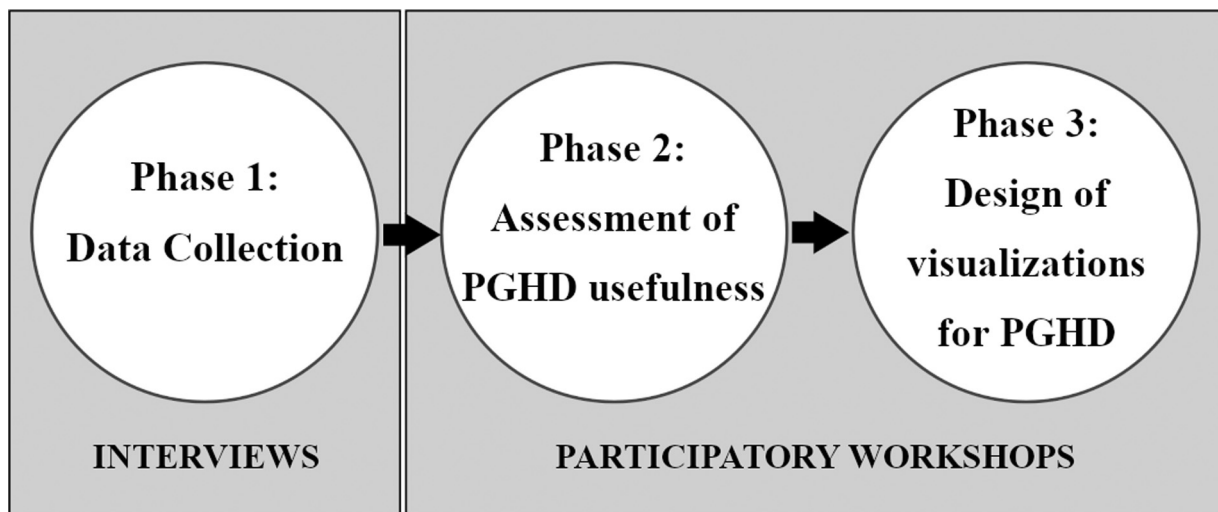
Fig. 1 Phases of the exploratory process.

thirds (12/16) of them having 10 or more years of experience. The workshops followed a consistent format, with G.G., V.M., and O.R.-R. facilitating the sessions. All facilitators had extensive experience moderating participatory workshops.

The categories and concepts identified during the data collection phase served as the foundation for the workshop's preparation. At the start of each workshop, participants were presented with trigger statements related to the two categories of concepts. The statement related to the category of mHealth for patient self-management was: *"As a health care professional, I would like my patient to be able to:"* and for the statement for the category PGHD for HCPs' use was: "*As a health care professional, I would like to know about my patient:"*. The concepts within each category were displayed on separate boards, sorted from the most frequently mentioned during the interviews to the least mentioned. Participants were not provided with information on the sorting criteria. The concepts associated with mHealth for patient self-management were presented first, followed by those in the category of PGHD for HCPs' use. After the trigger statement, participants had the opportunity to assess the concepts in that category and individually rank the three concepts they deemed most relevant based on their perceived utility in MS care. Afterwards, participants had brief discussions about the reasoning behind their choices.

While in real-life situations the decision to share PGHD rests with the patient, and privacy issues must be considered, for the purpose of the workshops, it was communicated to the participants that patients would be willing to share the data collected by the More Stamina app. This allowed HCPs to evaluate which of the datasets to be collected through the app could be useful if integrated into their workflow.

Design of Data Visualizations

Upon completion of the ranking exercise, participants were divided into design teams formed by three to four HCPs from diverse disciplines who shared a common interest in specific types of PGHD. Each team was instructed to work on a paper prototype of a visualization for the type of PGHD they deemed more useful. To provide a realistic context, a simple use case was provided. The visualization prototype was expected to be clear and concise enough to be reviewed within 5 minutes of a regular consultation with a PwMS. The prototype was intended to be a one-page view, providing useful information about the patient since the last check-up. Throughout the design process, participants had the opportunity to seek advice from the workshop facilitators. The facilitators emphasized important considerations, such as time constraints during appointments and potential issues of visualization ambiguity. The prototypes were constructed in the form of dashboard sketches.

HCPs' Experience as Participants in the Exploration Process

We believe that gathering feedback from HCPs representing different medical disciplines, working in diverse settings (inpatient/outpatient) and with various levels of experience in MS treatment, would contribute to enhancing the trustworthiness of the study by validating the utility of the types of PGHD collected in the earlier phase. Additionally, to gather recommendations for future related research, a couple of HCPs were invited to share their experience on the exploration process. These participants had joined the process starting at the interviews and participated in one of the workshops, although without prior knowledge of their later involvement in this study.

Ethical Considerations

The study was conducted following the ethical research guidelines of the University of Oulu and the Finnish Advisory Board on Research Ethics[41] and was approved by the Biomedical Research and Ethics Committee of the Junta de Andalucia in Spain.

As part of the More Stamina Project, ethical approval for the research was sought and obtained from the

corresponding entities in charge of research integrity in Spain and Switzerland.

Results

The exploration process comprised three interrelated phases, with each phase building upon the results of the previous one. The outcomes of the process are presented as follows.

Exploration of HCPs' Perceptions

In the first phase, data collection was done through interviews, which were subsequently analyzed. The analysis yielded several concepts related to the use of mHealth and PGHD. The category of concepts related to *mHealth for patient self-management* comprised 24 concepts, while the category of *PGHD for HCPs' use* incorporated 17 concepts (►Fig. 2).

During the interviews, 81.3% of HCPs ($n = 16$) agreed that mHealth solutions would be beneficial for their patients, while 43.8% indicated that they believed those solutions could also be useful for them in the care of PwMS. Among the participants, 50% reported having recommended health apps to their patients, primarily for education and prevention purposes. However, only two HCPs reported having previously reviewed PGHD from mHealth solutions during consultations.

The other two phases of the exploration process were conducted through a series of participatory workshops, focusing on the conceptualization of PGHD as a support tool for HCPs. The participants in the workshops had also been interviewed, providing them with the opportunity to reflect further on their initial perceptions of the utility of mHealth and PGHD in MS care.

During the exercise to rank the top three types of PGHD based on their perceived usefulness, HCPs' opinions in the category of *mHealth for patient self-management* varied widely, resulting in multiple data types being considered useful by only a few participants. In contrast, opinions seemed relatively more aligned in the category related to PGHD for HCPs' use. In this category, out of the 17 concepts identified from the interviews, only 10 were considered important during the ranking process. Furthermore, only five types of PGHD were found useful to four or more HCPs. The final ranking of the concepts is displayed in ►Fig. 3.

The results of the ranking process also indicate that, despite HCPs showing interest in objective PGHD, such as sleep quality and quantity or physical activity, the types of data ranked as more useful can be characterized as subjective. HCPs in MS care highly value data about habits and lifestyle, with over half (10/16) of them ranking those types of PGHD as the most useful. Other relevant types of subjective PGHD that produced interest include fatigue-inducing activities, mood, and stress. Responses from HCPs working in an inpatient clinic dedicated to physiotherapy indicated a slightly higher interest in digital biomarkers for HCPs in that medical discipline. Sleep quality and quantity and physical activity were identified as the most useful digital biomarkers from a solution as the More Stamina app.

In the final phase of the study, HCPs were required to design paper prototypes of PGHD visualizations that could be reviewed during a regular consultation. The prototypes were designed for the PGHD that HCPs ranked as the most useful in the context of MS care, namely habits and lifestyle, fatigue-
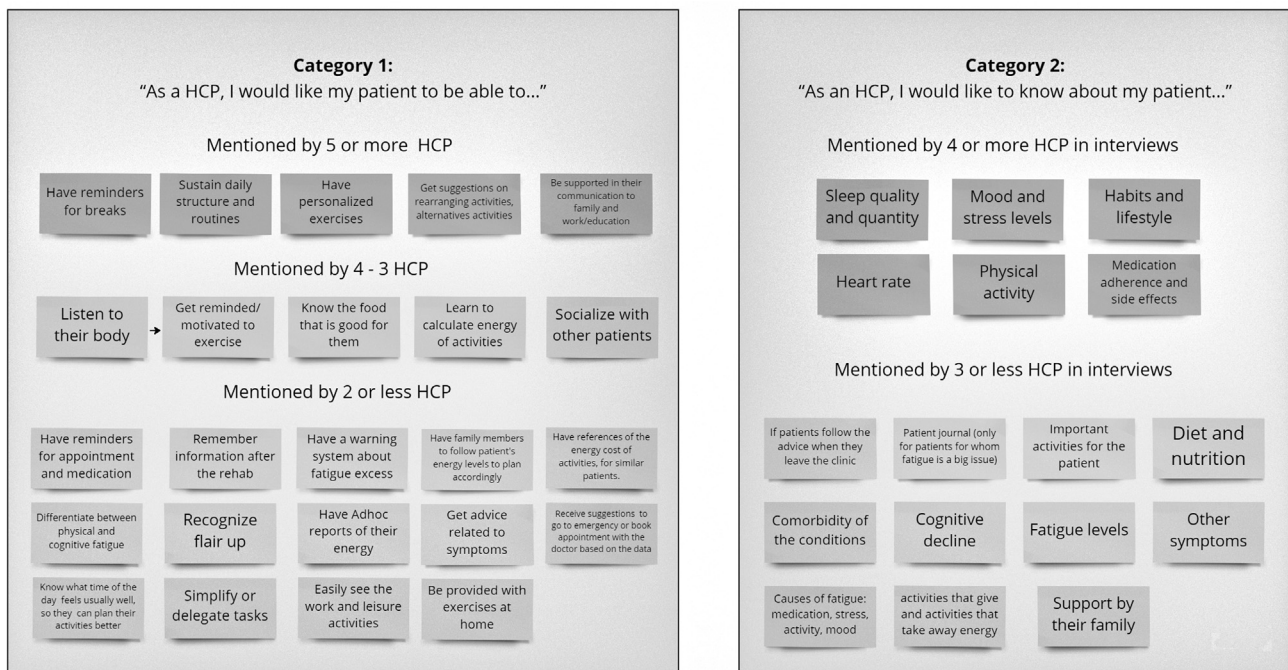

Fig. 2 Concepts related to mHealth and PGHD. PGHD, patient-generated health data.
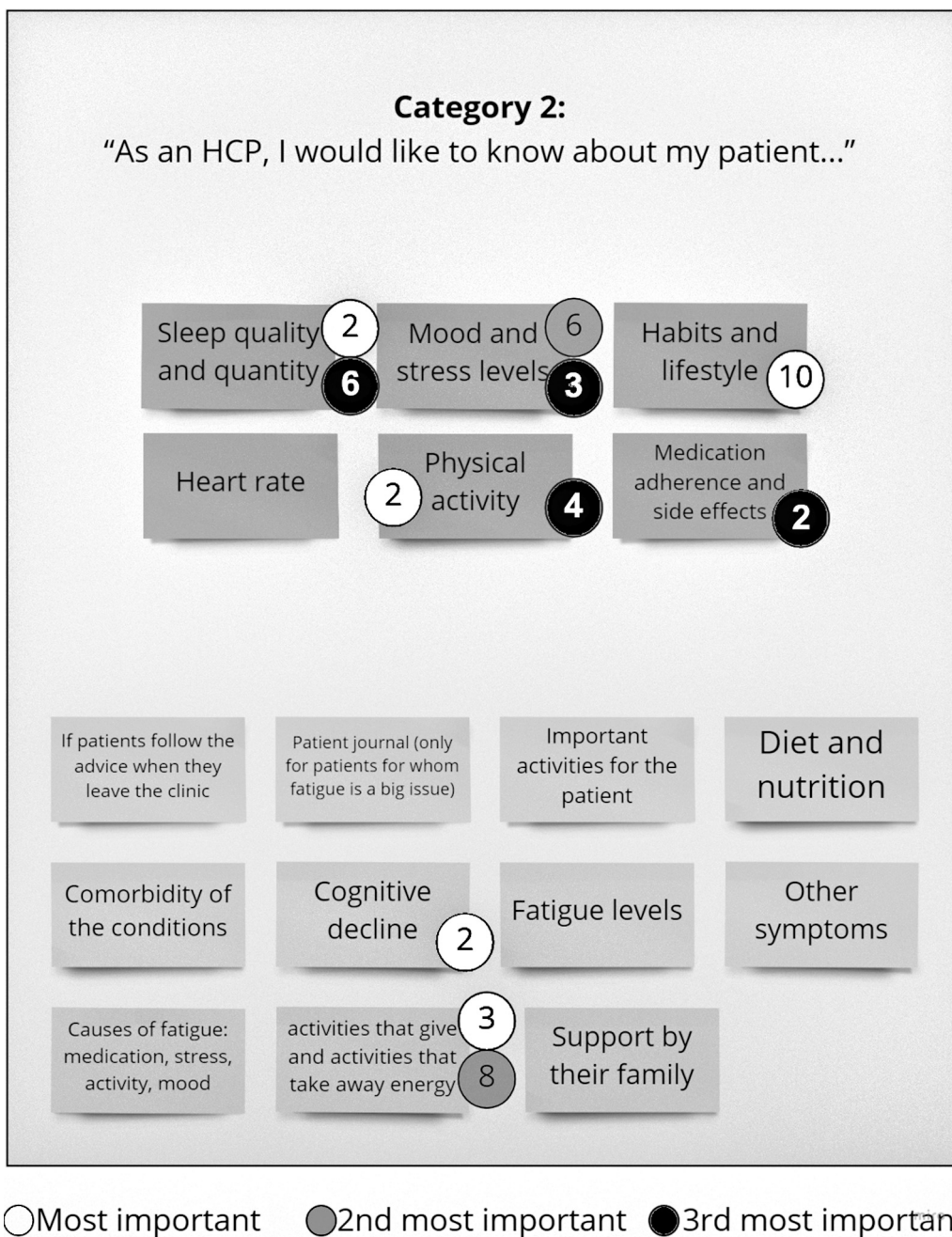
Fig. 3 Ranking of the usefulness of PGHD. PGHD, patient-generated health data.

inducing activities, sleep quality and quantity, and physical activity. An illustrative example of a prototype is shown in ►**Fig. 4**.

Lesson Learned for Further Studies
To address the secondary objective of our study, two of the participants in the exploration process shared their insights on the process. It is important to note that these participants were not involved in the data analysis or interpretation of the results.

Concerning the assessment of PGHD's usefulness, the participants indicated that selecting the three most useful concepts presented by the facilitators was challenging. In real life, HCPs need to consider multiple variables, including

collaboration with an interdisciplinary team of HCPs involved in care and the diverse goals of PwMS. The participants found the overall experience to be interesting and valued the opportunity to engage in discussions and share different thoughts with fellow HCPs. However, they indicated that the time allocated for the workshop was too short, as HCPs from different disciplines have varying viewpoints.

Discussion

Utility of PGHD in the Care of MS
This study aimed to explore the potential utility of different types of PGHD from an mHealth solution targeted at PwMS. The focus of the study was on the HCPs in MS care, as their
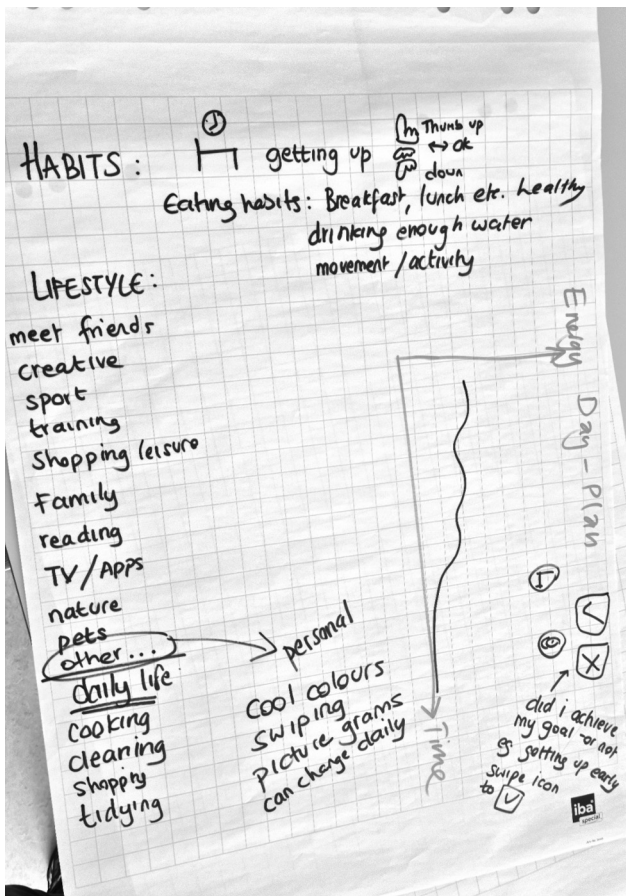
Fig. 4 Example of prototype for the visualization of habits and lifestyle.

perspective as stakeholders in the design process of mHealth solutions has been less studied.[42]

The use of mHealth solutions to enable PwMS in self-management has been on the rise, with nearly half of PwMS who own mobile devices reporting having used health apps and feeling they benefit in doing so.[13] However, the support for the active participation and engagement of the stakeholders with the use of mHealth solutions in the care process, namely HCPs, is still limited. Furthermore, HCPs may be hesitant to trust mHealth solutions until they identify the usefulness and value those solutions can provide in the clinical practice.[17,19] In this study, we found that HCPs expressed openness to mHealth and PGHD. They also showed a positive attitude toward their utility in MS care. Over 80% (13/16) of the participants believed mHealth solutions are beneficial tools to support patients in self-management, which is confirmed by the fact that half of them reported having recommended health apps to their patients in the past. However, HCPs are more reserved regarding the usefulness of PGHD for clinical purposes, with less than half (7/16) of them agreeing that it could serve them in MS care.

Previous studies have emphasized the added value of mHealth in MS care, particularly in providing additional information about patients.[15] This assertion aligns with the perception of the HCPs in our study, in which half of

them saw habits and lifestyle and fatigue-inducing activities as the type of PGHD they found more useful.

During consultations with PwMS, HCPs commonly inquire patients about their health, lifestyle, and well-being. Nevertheless, HCPs may feel hesitant to entirely trust PGHD from mHealth solutions to gain a comprehensive understanding of a patient's context and environment. In our study, despite the positive perceived attitude towards mHealth solutions, only two HCPs ($n = 16$) reported having utilized those solutions in their work to review PGHD or for other purposes.

It has been suggested that participatory health technologies such as mHealth solutions and different types of PGHD could positively impact HCPs' workload[30]; however, for this to be achieved in practice, extraordinary efforts need to be made on understanding how PGHD can be efficiently reviewed and made useful for HCPs in practical terms, overcoming challenges related to data validity and actionability.[1,22] The results of this study imply that most HCPs see the use of PGHD in MS care as an opportunity to understand patients beyond traditional metrics. We found that the types of PGHD ranked more useful can be characterized as subjective; however, when required to design data visualizations, only half of the teams focused on visualizations of subjective types of data, whereas the other half focused on designing visualizations for objective data such as sleep quality and quantity, and physical activity, seemingly pointing out to the challenge of visualizing and interpreting subjective PGHD to make it useful and actionable.

Throughout the study, HCPs expressed optimism about the opportunities provided by a mHealth solution like the More Stamina app to gain a better understanding of their patients, particularly regarding factors influencing fatigue, a prevalent and debilitating symptom of MS.[27] This finding aligns with recent research in MS, which has shown that employing mHealth solutions can enable HCPs to understand patients' fatigue levels and their response to treatment.[43] The validation of the habits and lifestyle being the most useful types of PGHD for HCPs relates to the principle of precision medicine, where care is personalized based on individual variability, including factors such as the patient's environment and lifestyle.[44] These factors can provide context to clinical data and facilitate communication and care.

Challenges and Improvement of the Method for further research

All the participants in the exploration process had experience in MS care. Together they represented seven different medical disciplines. This variation in the professional background of the participants may have influenced the differing opinions about the utility of different types of PGHD. This observation aligns with related research indicating that mHealth solutions provide better support for HCPs when they are targeted for specific patient groups, such as newly diagnosed patients or if they are designed to be used for specific functionalities only.[30]

During the exploration process, we identified that future efforts should concentrate not only on studying PGHD's

opportunities in the context of a specific health condition but also on its use for a more homogeneous array of medical disciplines or concrete clinical tasks. The feedback provided by the participants implies that while the collaborative-participatory design approach used is effective in fostering the appropriation of a digital solution,[40] it can be challenging for HCPs to apply their expert knowledge to create data visualization prototypes in the short time allocated for the activity. This issue must be considered in future implementations.

Limitations

All the participants had previous experience with patients reporting their habits and lifestyle in consultations. However, only a few of them had experience visualizing and reviewing these same data from mHealth solutions. This lack of experience with PGHD in the clinical context could have posed a challenge for some HCPs while attempting to design a visualization of PGHD. Thus, future studies should involve participants that have prior experience visualizing and reviewing PGHD in the care process. Although finding HCPs with such experience can be challenging, their inclusion would yield results based on more practical expertise.

A second limitation of this study was that all participants were recruited from specialized MS centers to prioritize their expertise in MS care. As a result, the findings of this study may not be generalizable to other contexts where HCPs work with patients presenting a wide range of health conditions. The results might be transferable to a similar context in either inpatient or outpatient settings; however, further research is required to validate the findings across diverse health care settings or countries with varying health care contexts.

Clinical or Public Health Implications of the Work

The unpredictable progression of MS, varying levels of disability, and a wide variety of potential symptoms result in each patient presenting a unique condition. MS requires highly individualized health care, often leading to the inability to work and negatively affecting the quality of life.[23] To address these challenges, it is crucial to provide PwMS with mHealth solutions that they can use in their daily lives to assist in self-management. Ideally, these tools could also serve HCPs in the care process. While HCPs express openness to integrating PGHD into their clinical workflow, the actual utilization of such data remains limited in practice. Through this study, we have identified that for HCPs in MS care, the most useful types of PGHD are patients' habits, lifestyles, and fatigue-inducing activities. HCPs were confident that these types of PGHD could be reviewed during consultations in a nondisruptive manner. However, further development and validation of the proposed data visualizations are necessary, while data security and privacy issues need to be addressed.

Conclusion

Through our exploratory study, we have identified that HCPs in MS care believe mHealth solutions can contribute to the objectives of PHI of improving health outcomes and achieving life goals. In the context of the More Stamina app, HCPs were optimistic about how this self-management solution can improve patients' well-being, while PGHD can enable them to further understand patients' individual needs and environment. The study revealed that HCPs from different medical disciplines hold different perceptions regarding the types of PGHD that are useful in MS care. Therefore, the design and implementation of mHealth solutions that will provide PGHD intended to be used in clinical workflows should consider the specific information needs of HCPs in different disciplines.

The HCPs in this study exhibited more interest in subjective data than in objective data. However, further research is required to understand how the subjective PGHD generated by mHealth solutions can be visualized and interpreted, ensuring it becomes actionable for both HCPs and PwMS.

Conflict of interest
None declared.

References

1 Lavallee DC, Lee JR, Austin E, et al. mHealth and patient generated health data: stakeholder perspectives on opportunities and barriers for transforming healthcare. mHealth 2020;6:8
2 Hsueh PY, Cheung YK, Dey S, et al. Added value from secondary use of person generated health data in consumer health informatics. Yearb Med Inform 2017;26(01):160–171
3 Sim I. Mobile devices and health. N Engl J Med 2019;381(10): 956–968
4 Dillenseger A, Weidemann ML, Trentzsch K, et al. Digital biomarkers in multiple sclerosis. Brain Sci 2021;11(11):1–26
5 Jeevanandan N, Nøhr C. Patient-generated health data in the clinic. In: Studies in Health Technology and Informatics. Vol. 270. Amsterdam: IOS Press; 2020:766–770
6 Feng S, Mäntymäki M, Dhir A, Salmela H. How self-tracking and the quantified self promote health and well-being: systematic review. J Med Internet Res 2021;23(09):e25171
7 Oh CY, Luo Y, St JB, Choe EK. Patients waiting for cues: information asymmetries and challenges in sharing patient-generated data in the clinic. Proc ACM Hum Comput Interact 2022;6(CSCW1):1–23

8 Gordon WJ, Landman A, Zhang H, Bates DW. Beyond validation: getting health apps into clinical practice. NPJ Digit Med 2020;3 (01):14

9 Vo V, Auroy L, Sarradon-Eck A. Patients' perceptions of mhealth apps: meta-ethnographic review of qualitative studies. JMIR Mhealth Uhealth 2019;7(07):e13817

10 Sarradon-Eck A, Bouchez T, Auroy L, Schuers M, Darmon D. Attitudes of general practitioners toward prescription of mobile health apps: qualitative study. JMIR Mhealth Uhealth 2021;9(03): e21795

11 Figueiredo MC, Chen Y. Patient-generated health data: dimensions, challenges, and open questions. Foundations and Trends in Human-Computer Interaction. 2020;13(03):165–297

12 Denecke K, Gabarron E, Petersen C, Merolli M. Defining participatory health informatics - a scoping review. Inform Health Soc Care 2021;46(03):234–243

13 Marrie RA, Leung S, Tyry T, Cutter GR, Fox R, Salter A. Use of eHealth and mHealth technology by persons with multiple sclerosis. Mult Scler Relat Disord 2019;27(27):13–19

14 Guardado S, Isomursu M, Giunti G. Health care professionals' perspectives on the uses of patient-generated health data. Stud Health Technol Inform 2022;294:750–754

15 Wendrich K, van Oirschot P, Martens MB, Heerings M, Jongen PJ, Krabbenborg L. Toward digital self-monitoring of multiple sclerosis: investigating first experiences, needs, and wishes of people with MS. Int J MS Care 2019;21(06):282–291

16 Chung CF, Dew K, Cole A et al. Boundary negotiating artifacts in personal informatics: patient-provider collaboration with patient-generated data. In: Proceedings of the ACM Conference on Computer Supported Cooperative Work, CSCW. Vol. 27; 2016: 770–786

17 Wannheden C, Åberg-Wennerholm M, Dahlberg M, et al. Digital health technologies enabling partnerships in chronic care management: scoping review. J Med Internet Res 2022;24(08):e38980

18 Rouidi M, Elouadi AE, Hamdoune A, Choujtani K, Chati A. TAM-UTAUT and the acceptance of remote healthcare technologies by healthcare professionals: a systematic review. Inform Med Unlocked 2022;32:101008

19 Jacob C, Sanchez-Vazquez A, Ivory C. Social, organizational, and technological factors impacting clinicians' adoption of mobile health tools: systematic literature review. JMIR Mhealth Uhealth 2020;8(02):e15935

20 Gourraud PA, Henry RG, Cree BAC, et al. Precision medicine in chronic disease management: the multiple sclerosis BioScreen. Ann Neurol 2014;76(05):633–642

21 Ward M, Goldman MD, Goldman MD. Epidemiology and pathophysiology of multiple sclerosis. Continuum (Minneap Minn) 2022;28(04):988–1005

22 Giunti G, Kool J, Rivera Romero O, Dorronzoro Zubiete E. Exploring the specific needs of persons with multiple sclerosis for mhealth solutions for physical activity: mixed-methods study. JMIR Mhealth Uhealth 2018;6(02):e37

23 Gil-González I, Martín-Rodríguez A, Conrad R, Pérez-San-Gregorio MÁ Quality of life in adults with multiple sclerosis: a systematic review. BMJ Open 2020;10(11):e041249

24 Marziniak M, Brichetto G, Feys P, Meyding-Lamadé U, Vernon K, Meuth SG. The use of digital and remote communication technologies as a tool for multiple sclerosis management: narrative review. JMIR Rehabil Assist Technol 2018;5(01):e5

25 Khan F, Amatya B. Rehabilitation in multiple sclerosis: a systematic review of systematic reviews. Arch Phys Med Rehabil 2017;98 (02):353–367

26 van der Walt A, Butzkueven H, Shin RK, et al. Developing a digital solution for remote assessment in multiple sclerosis: from concept to software as a medical device. Brain Sci 2021;11(09):1247

27 Barin L, Salmen A, Disanto G, et al; Swiss Multiple Sclerosis Registry (SMSR) The disease burden of Multiple Sclerosis from the individual and population perspective: which symptoms matter most? Mult Scler Relat Disord 2018;25:112–121

28 Ayobi A, Marshall P, Cox AL, Chen Y Quantifying the body and caring for the mind: self-tracking in multiple sclerosis. In: Conference on Human Factors in Computing Systems - Proceedings. Vol. 2017, May.; 2017:6889–6901

29 Van Kessel K, Babbage DR, Reay N, Miner-Williams WM, Kersten P. Mobile technology use by people experiencing multiple sclerosis fatigue: survey methodology. JMIR Mhealth Uhealth 2017;5(02): e6

30 Floch J, Vilarinho T, Zettl A, et al. Users' experiences of a mobile health self-management approach for the treatment of cystic fibrosis: mixed methods study. JMIR Mhealth Uhealth 2020;8 (07):e15896

31 Greiner P, Sawka A, Imison E. Patient and physician perspectives on MSdialog, an electronic PRO diary in multiple sclerosis. Patient 2015;8(06):541–550

32 De Angelis M, Lavorgna L, Carotenuto A, et al. Digital technology in clinical trials for multiple sclerosis: systematic review. J Clin Med 2021;10(11):2328

33 Bradway M, Gabarron E, Johansen M, et al. Methods and measures used to evaluate patient-operated mobile health interventions: scoping literature review. JMIR Mhealth Uhealth 2020;8(04): e16814

34 Giunti G, Mylonopoulou V, Rivera Romero O. More stamina, a gamified mHealth solution for persons with multiple sclerosis: research through design. JMIR Mhealth Uhealth 2018;6(03):e51

35 Giunti G, Rivera-Romero O, Kool J, et al. Evaluation of more stamina, a mobile app for fatigue management in persons with multiple sclerosis: protocol for a feasibility, acceptability, and usability study. JMIR Res Protoc 2020;9(08):e18196

36 Yrttiaho T, Isomursu M, Giunti G. Experiences using patient and public involvement in digital health research for multiple sclerosis. In: Studies in Health Technology and Informatics. Vol. 294. Amsterdam: IOS Press; 2022:735–739

37 Giunti G, Guisado Fernández E, Dorronzoro Zubiete E, Rivera Romero O. Supply and demand in mhealth apps for persons with multiple sclerosis: systematic search in app stores and scoping literature review. JMIR Mhealth Uhealth 2018;6(05): e10512

38 Giunti G, Haverinen J, Reponen J. Informing the product development of an mhealth solution for people with multiple sclerosis through early health technology assessment. Stud Health Technol Inform 2022;290:1042–1043

39 Namoun A, Daskalopoulou A, Mehandjiev N, Xun Z. Exploring mobile end user development: existing use and design factors. IEEE Trans Softw Eng 2016;42(10):960–976

40 Scariot CA, Heemann A, Padovani S. Understanding the collaborative-participatory design. Work 2012;41(Suppl 1):2701–2705

41 National Advisory Board on Research Ethics. Ethical principles of research in the humanities and social and behavioural sciences and proposals for ethical review. Published online 2009. Accessed September 4, 2023 at: https://tenk.fi/sites/default/files/2023-05/ RI_Guidelines_2023.pdf

42 Ozkaynak M, Sircar CM, Frye O, Valdez RS. A systematic review of design workshops for health information technologies. Informatics (MDPI) 2021;8(02):34

43 Block VJ, Bove R, Nourbakhsh B. The role of remote monitoring in evaluating fatigue in multiple sclerosis: a review. Front Neurol 2022;13:878313

44 Afzal M, Riazul Islam SM, Hussain M, Lee S. Precision medicine informatics: principles, prospects, and challenges. IEEE Access 2020;8:13593–13612