







Empowering patients: A multimodal digital health technology survey of patients with neurodegenerative disorders and immune-mediated inflammatory diseases

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Abstract

Objective: In an era where digital devices become increasingly available, passive and active capturing of patient data during their everyday life becomes possible. However, it is still unclear to what extent people with chronic diseases are willing to use digital health technology (DHT) to assess study-relevant endpoints. The aim of the present study was therefore to determine such acceptance rates for clinical studies and which type of DHT patients prefer.

Methods: A survey with 492 people with Parkinson's disease (64 ± 11 years, 41% female) and 75 people with an immune-mediated inflammatory disease (58 ± 15 years, 99% female) was conducted.

Results: The vast majority of people (93%) were willing to use at least two devices simultaneously during a clinical study. Two-thirds indicated that they would use DHT for ≥ 6 days following a visit in the context of a study. The appearance of the device turned out to be important as the most popular devices were smartwatches, whereas more complex DHT,

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clearly recognisable as medical-grade were least popular. The effects of gender, age and disease could be detected, such as, for example, a tendency for men to be willing to use more devices simultaneously than women.

Conclusion: Overall, our findings suggest a willingness among individuals with Parkinson's disease and immune-mediated inflammatory disease to engage in clinical studies involving DHT. It is also evident that elderly patients can be integrated into these studies provided that the participation demands are aligned with clinical imperatives and the devices are user friendly.

Keywords

Acceptance rates, device preferences, immune-mediated inflammatory disease, Parkinson's disease, user friendliness, wearable devices

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Introduction

Modern technologies, and especially mobile digital health technology (DHT), enable the passive and active capturing of patient data during their everyday life. Data collected by DHT can be used as a clinical endpoint or surrogate marker in clinical studies and support diagnosis, treatment decisions and could serve as assessments of therapeutic efficacy. The use of DHT in clinical trials has increased in the last years in accordance with the fast progression in technology development.^{1–3} With the evolution of technology, its application in clinical trials also evolves. A range of technologies is utilised to gather multimodal data, with capabilities in capturing diverse data types concurrently.² While the use of DHT in clinical studies is growing in recent years, its use is heterogeneous: Some clinical studies are carried out for DHT verification purposes (the “hardware”) or the validation of novel biomarkers or endpoints (the “software”), others apply already available DHT biomarkers or endpoints.² Recently, the U.S. Food and Drug Administration has launched recommendations for sponsors, investigators, and other stakeholders on the use of DHT for remote data acquisition from participants in clinical investigations that evaluate medical products.⁴ However, whereas Chandrasekaran et al.⁵ asserted in 2020 that up to 70% of clinical trials would incorporate DHT by 2025, the deployment of DHT in clinical research is currently surprisingly limited. One of the main reasons is the fear that the use of DHT is too much burden for study participants, which could have an impact on data quality.⁶ The Electronic Clinical Outcome Assessment consortium⁷ emphasizes the importance to select DHT that have good usability properties with the specific population in mind.⁶

There is still little evidence on how willing people with chronic diseases are to use DHT for research purposes in their daily life. It may depend on several factors. A motivating factor is a possible diagnostic or therapeutic benefit for the participants and loved ones through the study participation.⁸ Negative factors are the burden of participation and concerns about data protection and privacy.^{8–11} In a survey, site staff said that participants' willingness to use DHT depends on

age, disease severity, frequency of data collection, previous experience with healthcare technology and problems to connect devices. The effort required to learn how to use the technology in the study and the burden of carrying an additional device were also cited as demotivating factors.¹¹ Finally, another key point in prior literature was that the use of this technology is not usually sustained.^{12,13}

There is little prospective research regarding practical matters such as the time patients are willing to dedicate to research studies with DHT and which type of DHT they would prefer. A recent study found that key factors that determine the acceptability of medical devices for home use include low effort of use, minor disruptions to daily live and good support from the study team.¹⁴ An international survey collecting patient perspectives on DHT in care and clinical trials performed with people suffering from motor neuron disease investigated patients' preferences for the number of apps/devices to use and frequency for home monitoring. Patients stated that they find a maximal number of three to four devices or assessments to use at home acceptable and that the highest acceptable frequency is weekly.¹⁵ Table 1 shows a summary of the current state of knowledge concerning this topic.

This study seeks to address key questions concerning the acceptance of DHT by persons with chronic conditions. Specifically, we aim to determine which types of DHT these people are most willing to use, for what duration and under what conditions they find such technologies acceptable. Additionally, we investigate how demographic factors, such as age and disease type, influence DHT preferences and potential adherence in clinical research settings.

Methods

Participants

Patients with either Parkinson's disease (PD), Huntington's disease (HD) or at least one immune-mediated inflammatory disease (IMID; rheumatoid arthritis [RA], systemic

Table 1. Literature-based factors influencing the willingness to use of digital health technology.

Motivating factors	Demotivating factors
<ul style="list-style-type: none"> - Possible diagnostic or therapeutic benefit⁸ - Good support from study team¹⁴ 	<ul style="list-style-type: none"> - Burden of participation: high effort of use¹⁴ and time commitment^{9,10} - Concerns about data protection and privacy¹⁵ - High frequency of active data collection¹⁵ - Disruption of daily life¹⁴

lupus erythematosus [SLE], Primary Sjögren's Syndrome [PSS], or inflammatory bowel disease) were invited to participate in this online survey. The only inclusion criterion was the presence of one of these diseases, and there were no exclusion criteria. Clinical confirmation of the diagnosis and having already experience with DHT was not required.

Survey

This survey was developed with the aim of gathering anonymous feedback from people affected by these diseases to help design a large multicentre observational study and to understand what patients would deem acceptable in terms of study design. Therefore, questions regarding the preferences people have concerning clinical study participation in general and DHT use in particular were included. The questions were developed by IDEA-FAST (*Identifying Digital Endpoints to Assess Fatigue, Sleep and activities of daily living in Neuro-degenerative disorders and Immune-mediated inflammatory diseases*) consortium partners including patient specialists. No copyright permissions are needed. The survey was set up with Lime Survey (LimeSurvey GmbH, Hamburg, Germany). Data were stored on a server by Alfahosting,¹⁶ all located in Germany. Questions were first developed in English, then translated into French, German, Italian and Spanish using DeepL¹⁷ and proofread by native speaking study staff for each language. The survey design was adapted from other initiatives.^{18–20}

Ethics approval for the survey design and content were received by the ethics committee of the medical faculty of Kiel University prior to study start (D 547/21). The aim was to collect information for the design of this study, which uses DHT in these patient groups. The link of the survey was sent out via email to the following organizations and patient groups for further distribution: European Federation of Crohn's & Ulcerative Colitis Associations, Asociación Parkinson Madrid, Parkinson's UK, Lupus UK, Sjogren Europe, European Huntington Association, and University of Newcastle. It was also made available to patients in France, Germany, Italy, Spain and the United Kingdom, especially to those patients who were involved in the

IDEA-FAST feasibility study ($N = 145^{21,22}$). It was available for completion 147 days from 10 August 2021 to 1 February 2022 and was available only online. Before potential responders could start filling out the survey, they were informed in writing about the content of the survey and how obtained data will be processed. They had to actively agree to participate by clicking their mouse. Otherwise, the process stopped, and no data were stored. Participation in the survey was voluntary, and participants did not receive any compensation for completing it.

The survey contained two major sections. In the first section, participants answered 15 questions regarding technology, its use and use duration. In the second section, 10 questions gathered basic demographic data such as, for example, age, gender, country of residence, disease duration and the current condition of the disease-related symptoms such as fatigue and sleep disorders, the main topics of the study to design. The completion of the survey took about 10 min. The full survey is available in the supplementary material.

Selected questions about device use

The focus of this analysis was on the following questions concerning device use.

- Question 5 (Q5): "If you were asked to wear two devices that were simple to use, for how many days would you be happy to wear them together? This could be a smartwatch and a movement sensor at your lower back as indicated in the photo below, which can be worn hidden from view under your clothes. The devices have to be worn continuously 24h per day and should only be removed from the body during showers, and so on. Correct placement needs to be checked daily and the devices may need to be recharged once or twice per week," with the following possible answers: "2 days or less; 3–5 days; 6–7 days; 8–14 days; 15 days or longer" (see Appendix figure A1).
- Question 6 (Q6): "Which sort of devices would you be willing to use [you can choose more than one option]? The devices can be worn hidden from view under your clothes," with the following possible answers (including picture of device): "a. Smartwatch (wrist band with display)*; b. Wrist band without display (otherwise similar to a.)*; c. Waist belt*; d. Arm band*; e. A patch that sticks to your chest*; f. A head band that you wear at night*; g. A mat that you place under your mattress*; h. A small box placed on your bedside*; i. Any device that is safe for use (e.g., with a security certificate); j. None. (explications: * Devices that measure mobility and/or physiological function, such as steps and heart rate, **Devices that measure your sleep)."

- Question 7 (Q7): “We are considering asking people to use more than one device in order to be able to collect a broader range of measures. How many devices would you be willing to use (together)?” with the following possible answers: “1; 2; 3; 4; 5 or more.”
- Question 8 (Q8): “Would you prefer stationary or wearable devices (please choose “0” if you don’t have any preference)?” where people should indicate their preference on a scale from -5 (*strongly prefer stationary device*) to 5 (*strongly prefer wearable*).
- Question 13 (Q13): “Would you be willing to enter these data (on your fatigue, sleep and health) into an app installed on your own smartphone? The study team could assist in installing the app if needed,” with the following possible answers: “Yes; No, because I would be concerned about the app accessing data from my phone; I do not own a smartphone.”
- Question 14 (Q14): “How regularly would you like feedback about the data collected by the devices you are using for the study, if this is possible?” with the following possible answers: “Every day; After each visit in connection with the use of digital devices; Once, at the end of the study; I do not want to get any feedback from the digital devices.”

Statistical analysis

JASP (Version 0.18.3, JASP Team, 2024) was used for analysis, and JASP and Excel (Version 16.0.4266.1001, Microsoft Corporation, 2016) for visualisation of results. Variables are presented as mean (\pm standard deviation) or frequency (%). To compare different age groups, the data were split into the following four quartiles: ≤ 55 years, 56–63 years, 64–71 years, and ≥ 72 years. An α level $< .05$ was considered statistically significant. In general, chi square tests were performed, as the data were categorical. For question 8 a Mann-Whitney U test was performed, as the data were categorical and not normally distributed. For question 6, multiple chi square tests were performed and Bonferroni corrected.

Results

Demographics

In total, 1439 participants started and 631 of those completed the survey (44%). Eight hundred and eight survey takers accessed the link to the survey but did not make any entries. As the survey was anonymous, it is not possible to determine whether there were any participants who later completed the survey. Of those 567 were included in the final analysis, 493 PD patients and 75 patients with at least

one IMID (32 PSS; 19 SLE; 5 IBD; 1 RA; 7 RA and PSS; 7 SLE and PSS; 3 RA and SLE; and 1 RA, SLE and PSS). We excluded 27 HD patients due to small sample size (descriptive results presented in the supplementary material), 20 patients with both, PD and IMID diagnosis, 9 who did not want to disclose their diagnosis and 8 participants without any disease. Basic demographics of the PD and IMID groups are presented in Table 2.

The PD group was older than the IMID group and included more males. Most PD participants indicated that their country of origin was Spain, while the majority of the IMID participants were from the United Kingdom. For further information, please see Supplementary Table S1.

A high percentage of the survey completers had the above-mentioned diseases for ≥ 2 years or longer: Almost 90% of respondents indicated that the onset of the disease was at least 2 years ago and more than half indicated that it was at least 5 years ago. The majority of IMID participants indicated that they suffered from the disease for more than 10 years.

Survey answers

Table S3 gives an overview of group-specific differences. In the following the results of the survey questions are presented.

Time respondents would be willing to use two devices at the same time (question 5). All respondents said they would use two devices at the same time for up to 2 days, 88% would be willing to wear them for up to 5 days, 66% for up to 7 days, 46% for up to 14 days and 37% would be willing to wear them for 15 days or more (Figure 1B). Older age was associated with shorter periods the survey takers would be willing to use DHT ($p = .004$). No significant differences between disease groups and gender were observed (Supplementary Table S2).

Type of device respondents prefer to use (question 6). Smartwatches were deemed most acceptable by respondents (74% were willing to use this device), while the chest patch (34%; e.g., for collection of physiological data) and the head band (e.g., for the nighttime collection of electroencephalograms (EEG); 24%) were rated least acceptable. People with an IMID were more likely to indicate their willingness to use the chest patch, the bed mat, the wrist band without display, the arm band and the box at the bedside compared to people with PD. The younger age groups indicated a greater willingness to use the head band and the chest patch than participants from the older age groups. More female participants were willing to use the bed mat, the wrist band without display and the box at the bedside compared to male participants (Figure 2).

Table 2. Basic demographics of the PD and IMID groups.

Group	N	Age (years), mean (SD)	Female, n (%)	No symptoms	<1 year	1–2 years	2–5 years	5–10 years	>10 years	Prefer not to disclose	No answer
PD, n (%)	492	64 (11)	200 (41)	0	15 (3)	42 (9)	159 (32)	151 (31)	112 (23)	6 (1)	7 (1)
IMID, n (%)	75	58 (15)	74 (99)	4 (5)	0	2 (3)	8 (11)	17 (23)	44 (59)	0	0
Group comparison		t = -4.0 (p < .001)									
			$\chi^2=87.7$ (p < .001)								

Note: IMID: immune-mediated inflammatory disease; PD: Parkinson's disease.

Number of devices respondents would be willing to use (question 7). All respondents said they would accept a digital device for data collection in their usual environment. When the only option was to wear more than one device, 93% of the respondents were willing to wear two devices, 56% three devices, 30% four devices, and 22% five or more devices. Men were more open to wearing more than one device simultaneously than women ($p < .001$). There were no significant differences in this question between the diseases studied or any association with age (Figure 1C).

Preferences of respondents concerning stationary or wearable devices (question 8). The majority (57%) did not show a preference, while 14% showed a strong preference for wearables and 6% showed a strong preference for stationary DHT (Figure 3). Older age was associated with a preference for stationary devices ($p = .027$). There was no significant association in preference in disease groups ($p = .207$) or per gender ($p = .353$).

Willingness of respondents to install and use a (diary) app for study purposes on their own smartphone (question 13). Most respondents (81%) were willing to install and use an app on their own smartphone for study purposes. Only 8% were not willing to do so, while 11% said they did not own a smartphone. Younger age ($p < .001$) and male gender ($p = .021$) were associated with greater willingness to install and use an app on their personal smartphone for a study. There was no significant association for disease groups ($p = .806$; data not shown).

Feedback frequency of device data desired by respondents (question 14). When asked how often they would like to receive feedback about the data collected by the DHT (e.g., time spent in vigorous or moderate activity, or sleep duration) about 99% of respondents indicated that they would like to receive it. Most respondents (47%) indicated a preference for receiving feedback after each technology use period, while 29% indicated a preference for feedback at the end of the study, 24% were in favour for daily feedback, and 1% for no feedback at all. Technology use period describes the period of time during which a subject wears/uses DHT. More people with PD wanted to receive daily feedback (PD: 25%, IMID: 12%), while more people with an IMID wanted to receive feedback only once (PD: 27%, IMID: 40%; $p = 0.022$). Age group ($p = .091$) and gender ($p = .113$) did not show a significant effect (Figure 1A).

Discussion

DHTs are increasingly used in clinical trials.^{2,3,5,23–25} The Clinical Trials Transformation Initiative lists five points they would like to see changed in clinical trials by 2030. One of them covers the selection of DHT for clinical

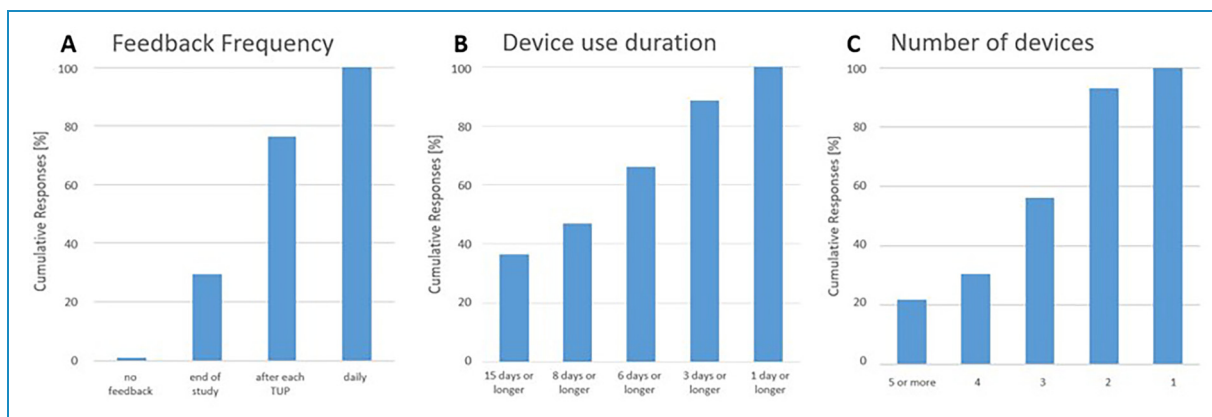


Figure 1. Indicated preferences regarding feedback frequency (A), device use duration (B), and the number of DHT people with PD and IMID would be willing to use during a potential study or trial (C). Technology use period represents a defined continuous assessment period.

Note. DHT: digital health technology; PD: Parkinson's disease; IMID: immune-mediated inflammatory diseases.

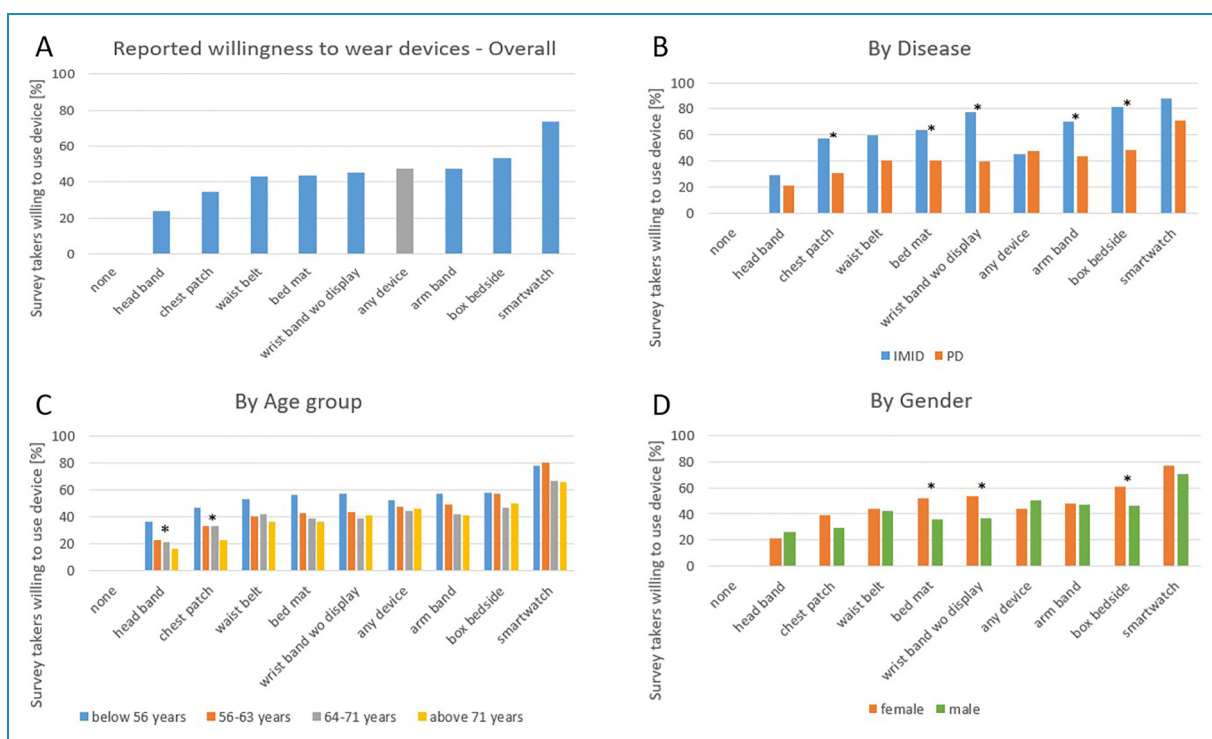


Figure 2. Percentage of respondents willing to use specific DHT. (A) Overall, (B) by disease (PD vs. IMID), (C) by age group and (D) by gender.

Note. DHT: digital health technology; PD: Parkinson's disease; IMID: immune-mediated inflammatory diseases.

* $p < .05$.

research.²⁶ The hope is that DHT can collect a maximum of study data passively and non-invasively minimizing the manual collection of trial-specific data. One of the most important advantages of DHT is that they can capture patients' data in a more realistic, i.e. everyday life, environment.^{27,28} Another advantage is that mobile technologies can reduce the burden of a study participation because

less on-site visits are necessary. On the other hand, the burden can also increase for participants who are not familiar with digital devices or for those who are physically impaired due to their disease which makes the use of DHT difficult (an example could be a touch screen that is difficult to use for a person with reduced fine motor skills). These challenges might be overcome, but careful design

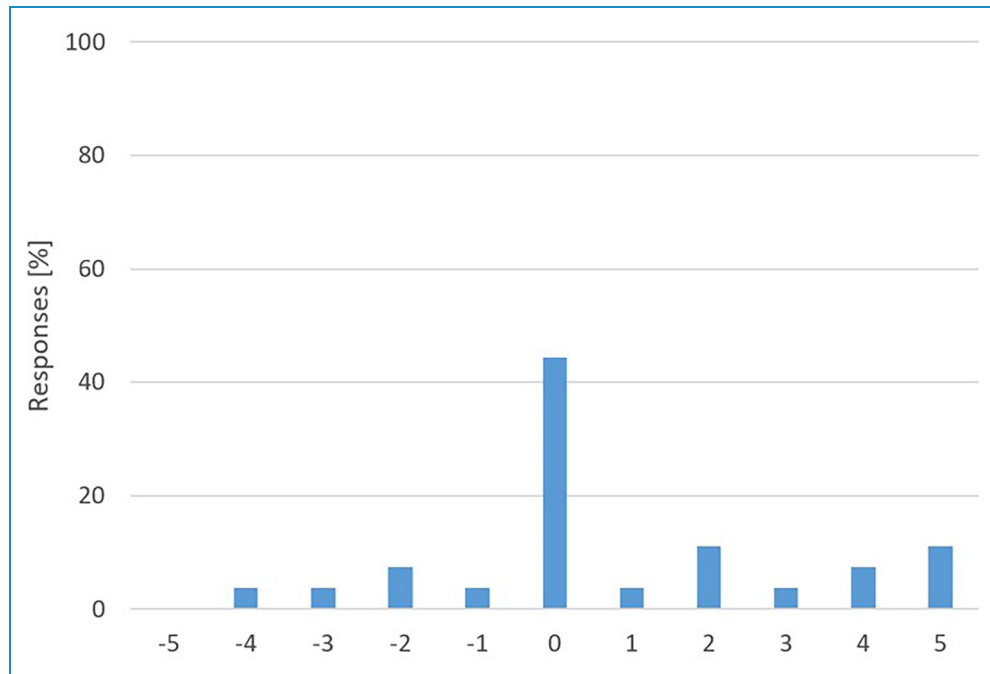


Figure 3. Reported preference for stationary or wearable DHT across all participants. -5 indicates a strong preference for stationary devices, 5 indicates a strong preference for wearables, while zero indicates no preference.

and testing of DHT in specific contexts of use and diseases is therefore important.

In the survey presented here, we tried to assess how a clinical study or trial with DHT should be designed to be well accepted by different groups of people with a disease. We found that DHT use for research purposes is well accepted in people with chronic diseases, such as PD and IMID. All people were willing to use such technology for research purposes. Most respondents were willing to use at least two devices for at least 3 days (with two-thirds willing to use DHT for at least a week) and they were willing to install an app on their own phone for research purposes. In the last decade, several publications investigated the use of mobile technologies in clinical trials,^{23,29–32} highlighting the potential of unobtrusive data acquisition as well as the need to adjust the length and type of device to the target population. Data frequently collected over extended periods of time could provide deeper understanding of disease activity variability, a likely important contributor to treatment response variability. Having larger and denser datasets would help to characterize intra- and interpatient variability. However, if use periods are too long this is likely to decrease adherence.³³ Therefore, our data give valuable insights on which DHT and use lengths might be acceptable to clinical populations.

In our data, there was no clear preference given to the choice between wearable or stationary DHT. When looking at the exact type of device participant's preferred, unsurprisingly, those devices that were frequently used in everyday life, such as smartwatches, were preferred as well as devices that needed little attention, like a box on the nightstand to measure vital

parameters. People were least willing to use a headband during the night. Reasons might include that this device is unusual and very visible, might interfere with the normal sleep position and must be put on correctly every night. Qualitative research shows that, indeed, concerns with the visibility of a device as well as expected reactions of peers and the hassle to use a device are important factors for research participants when using DHT.¹⁴ A meta-synthesis of qualitative research on DHT also found that people disliked devices that resemble medical devices and those they had to wear in bed.³⁴ This might also explain why the chest patch was not very well liked, as it resembles a medical device.

Looking at a group level, we found that the diagnosis influenced the willingness to use digital technology for some parameters. A larger proportion of people with IMID were willing to use the chest patch, the bed mat, the wrist band without display, the arm band and the box at the bedside compared to people with PD. A reason for this difference might be that motor symptoms that are more prominent in PD might be a concern when interacting with certain DHT. Another possible explanation might be that all these DHT are not very well known and PD patients show decreased novelty seeking.³⁵ Therefore, PD patients might be more prone to liking established devices like, for example, a smart watch. Another difference between the two disease groups was that more people with PD would like to receive daily feedback, while more people with an IMID would prefer feedback only once. A practical reason might be that PD patients are older and therefore more likely to be unemployed 5 years after diagnosis³⁶ compared

to PSS (and RA),³⁷ for example, and thus might have more time to process the feedback. In general, it can be said that feedback is extremely important for the respondents and that it should also be given on a relatively frequent basis.

Recent studies reported older study participants showing lower familiarity with DHT and requiring greater technical support.³⁸ Lower acceptability in the use of mobile technology was also observed.^{39–44} Yet, only few studies can be found that look at patients' preferences of the use of mobile technologies in clinical studies prospectively. It is crucial to understand if and to what extent potential study participants are willing to use DHT when designing a study.³² In our study, which included relatively old people with chronic diseases, we observed small effects due to age indicative that also older people have a high willingness to use DHT for clinical research. This is in line with a study showing very good adherence of a smartphone study in older adults.³⁸ However, younger people were more willing to install apps for the study on their own phone than older people. This could be because younger people are already familiar with the use of apps and the exchange of data via apps and are less concerned about the data being misused. In addition, in our survey, older participants preferred shorter use periods for the DHT and were less willing to use the head band and the chest patch than younger participants. The survey also showed that some older people would prefer stationary DHT. Therefore, the use of complex wearables should be well thought out in older populations as this might overwhelm them. Also, DHT use periods should be kept shorter than in younger populations. Zin et al.⁴⁵ showed that physical constraints and a lack of technical understanding caused elderly Koreans to struggle with the use of DHT. So, the decreased motor and cognitive functioning, that can occur with advanced age, and particularly in PD and HD, may also contribute to this result to some extent.

In our study, some effects of gender were detected as well. For some DHT (e.g., bed mat, wrist band without display, or box at the bedside), women were more likely to indicate that they would use the device than men. One explanation could be that women might be more motivated to participate in studies for altruistic reasons irrespective of the device they were asked to use.⁴⁶ On the other hand, men were more willing to wear several DHT at the same time and more willing to use study apps on their own phone than women, which also shows high motivation in men for study participation in general. One could hypothesize that men like to interact with DHT and like the complexity that comes with the use of multiple DHT more than women do. However, this might also be the expression of a social impact of a study participation in general, a higher risk-taking behaviour observed in men and higher mistrust in women as key factors for willingness to participate in clinical trials.⁴⁷ Furthermore, it has been shown that women more than men fear that the use of DHT might effect in less human attention and could lead to loneliness or social isolation,⁴⁸

and when it comes to adopting new types of wearable technology, women lag behind.⁴⁹ Our results need confirmation in future studies and hypotheses for gender-specific preferences should be tested to improve retention rates for these types of studies.

Limitations

Several factors limit the generalizability of our results. First, the PD and IMID groups are not comparable in terms of gender (PD mostly male, IMID almost exclusively female) and country of residence (the majority of survey responders indicated living in Spain (54%) followed by the United Kingdom (11%). The rest was distributed all over Europe, with relatively low numbers per country. Almost all of the Spain responders were people with PD. Hence, the effects of gender and disease in this sample should be interpreted with caution. Second, we did not assess how prior DHT use impacts willingness to use technology in research. It may make sense to take this factor into consideration in future studies, as one study showed that people using mobile devices daily were more willing to participate in a clinical trial using DHT.³² Third, we did not assess the potential adverse health effects associated with prolonged utilisation of DHT. This encompasses general negative impacts on brain health and specific concerns related to PD, such as impulse control disorders. We would therefore like to emphasise the importance maintaining a balanced approach toward the utilisation of these technologies. Fourth, we must acknowledge the possibility of selection bias as also participants of the IDEA-FAST feasibility study were informed about the survey. Although this could only have been a minority, it is still possible that their contribution introduced a bias toward higher experience with the use of some of the devices (and accepting some burden of collecting additional information through them), computer literacy and interest in clinical innovation. Fifth, as the survey focused on a selection of devices used in the IDEA-FAST feasibility study, the questions were designed by IDEA-FAST consortium partners, and the wording of the questions may have influenced the respondents' choices. Sixth, the survey questions were not formally validated. However, the wording of the questions was refined through several rounds of discussion with patient specialists to improve the comprehensibility and usability of the questions and eventually obtain the most precise answers possible. Seventh, information about educational background, cognitive ability and prior experience with DHT were not collected. Finally, the diagnoses were not confirmed by a medical doctor.

Conclusion


Patient engagement and a patient-centric study design are crucial to enable the efficient use of DHT in clinical studies. To avoid drop-outs, non-compliance and invalid


device data the type of DHT and the use duration should be considered carefully. Our data indicate that the optimal duration for DHT assessment periods involving people with chronic diseases ranges from 3 to 7 days, employing a maximum of two devices. Smartwatches are currently the most widely accepted type of device. Overall, our results are encouraging regarding the future implementation of DHT in clinical studies, as they show that not only younger but also older and chronically ill people are interested to participate in technology-added studies as long as devices are easy to use, and the participation effort is manageable.


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Ethical considerations

Ethics approval for the survey design and content were received by the ethics committee of the medical faculty of Kiel University prior to study start (D 547/21).

Consent to participate

All study participants were informed of the objective of this survey, how it was carried out and what participation meant. They provided online consent to voluntary participate in the study and to the use of their data for scientific work.

Author contribution

KE, WM, WFN, and HK designed and supervised the project.

CM, JG, DS, AP, AP, RR, MWR, NM, HK, SiH, RB, and FB helped designing the project.

CM, JG, LA, CB, PH, JJR, DDS, LW and SoH carried out the project.

CM and KE performed the analyses.

All authors discussed the results and contributed to the final article.

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Declaration of conflicting interest

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Data availability

All data presented in this publication can be made available upon request.

Supplemental material

Supplemental material for this article is available online.

References

1. *Library of Digital Endpoints*. Digital Medicine Society (DiMe), <https://dimesociety.org/library-of-digital-endpoints/> (accessed 7 November 2024).
2. Masanneck L, Gieseler P, Gordon WJ, et al. Evidence from ClinicalTrials.gov on the growth of digital health technologies in neurology trials. *NPJ Digit Med* 2023; 6: 23.
3. Pyper E, McKeown S, Hartmann-Boyce J, et al. Digital health technology for real-world clinical outcome measurement using patient-generated data: systematic scoping review. *J Med Internet Res* 2023; 25: e46992.
4. U.S. Department of Health and Human Services Food and Drug Administration. Digital Health technologies for remote data acquisition in clinical investigations, <https://www.fda.gov/media/155022/download> (2023, accessed 8 September 2025).
5. Chandrasekaran R, Katthula V and Moustakas E. Patterns of use and key predictors for the use of wearable health care devices by US adults: insights from a national survey. *J Med Internet Res* 2020; 22: e22443.
6. Izmailova ES, Middleton D, Yunis R, et al. Implementing sensor-based digital health technologies in clinical trials: key considerations from the eCOA consortium. *Clin Transl Sci* 2024; 17: e70054.
7. *Electronic Clinical Outcome Assessment (eCOA) Consortium*, <https://c-path.org/program/electronic-clinical-outcome-assessment-consortium/> (accessed 8 September 2025).
8. Bardach SH, Holmes SD and Jicha GA. Motivators for Alzheimer's disease clinical trial participation. *Aging Clin Exp Res* 2018; 30: 209–212.
9. Bevan EG, Chee LC, McGhee SM, et al. Patients' attitudes to participation in clinical trials. *Br J Clin Pharmacol* 1993; 35: 204–207.
10. Gaul C, Schmidt T, Helm J, et al. Motivation und Barrieren für die Teilnahme an klinischen Studien. *Med Klin* 2006; 101: 873–879.
11. Polhemus AM, Kadhim H, Barnes S, et al. Accelerating adoption of patient-facing technologies in clinical trials: a pharmaceutical industry perspective on opportunities and challenges. *Ther Innov Regul Sci* 2019; 53: 8–24.
12. Laar A, Silva de Lima AL, Maas BR, et al. Successful implementation of technology in the management of Parkinson's

- disease: barriers and facilitators. *Clin Park Relat Disord* 2023; 8: 100188.
13. Riggare S, Stamford J and Hägglund M. A long way to go: patient perspectives on digital health for Parkinson's disease. *J Park Dis* 2021; 11: S5–S10.
 14. Graeber J, Warmerdam E, Aufenberg S, et al. Technology acceptance of digital devices for home use: qualitative results of a mixed methods study. *Digit Health* 2023; 9: 205520 76231181239.
 15. Helleman J, Johnson B, Holdom C, et al. Patient perspectives on digital healthcare technology in care and clinical trials for motor neuron disease: an international survey. *J Neurol* 2022; 269: 6003–6013.
 16. *Alfahosting*. <https://alfahosting.de/> (accessed 8 September 2025).
 17. *DeepL*. www.deepl.com/ (accessed 8 September 2025).
 18. Tran V-T, Riveros C and Ravaud P. Patients' views of wearable devices and AI in healthcare: findings from the ComPaRe e-cohort. *NPJ Digit Med* 2019; 2: 53.
 19. Creagh AP, Hamy V, Yuan H, et al. Digital health technologies and machine learning augment patient reported outcomes to remotely characterise rheumatoid arthritis. *NPJ Digit Med* 2024; 7: 33.
 20. Tortelli R, Rodrigues FB and Wild EJ. The use of wearable/portable digital sensors in Huntington's disease: a systematic review. *Parkinsonism Relat Disord* 2021; 83: 93–104.
 21. Antikainen E, Njoum H, Kudelka J, et al. Assessing fatigue and sleep in chronic diseases using physiological signals from wearables: a pilot study. *Front Physiol* 2022; 13: 968185.
 22. Romijnders R, Atrsaei A, Rehman RZU, et al. Association of real life postural transitions kinematics with fatigue in neurodegenerative and immune diseases. *NPJ Digit Med* 2025; 8: 12.
 23. Perry B, Herrington W, Goldsack JC, et al. Use of Mobile devices to measure outcomes in clinical research, 2010–2016: a systematic literature review. *Digit Biomark* 2018; 2: 11–30.
 24. Rosa C, Campbell ANC, Miele GM, et al. Using e-technologies in clinical trials. *Contemp Clin Trials* 2015; 45: 41–54.
 25. Rosa C, Marsch LA, Winstanley EL, et al. Using digital technologies in clinical trials: current and future applications. *Contemp Clin Trials* 2021; 100: 106219.
 26. Clinical Trials Transformation Initiative - Digital Health Trials. <https://ctti-clinicaltrials.org/our-work/digital-health-trials> (accessed 8 September 2025).
 27. Maetzer W, Rochester L, Bhidayasiri R, et al. Modernizing daily function assessment in Parkinson's disease using capacity, perception, and performance measures. *Mov Disord Off J Mov Disord Soc* 2021; 36: 76–82.
 28. Perry B, Kehoe L, Swezey T, et al. How much evidence is enough? Research sponsor experiences seeking regulatory acceptance of digital health technology-derived endpoints. *Digit Biomark* 2023; 7: 45–53.
 29. Bakker JP, Goldsack JC, Clarke M, et al. A systematic review of feasibility studies promoting the use of mobile technologies in clinical research. *NPJ Digit Med* 2019; 2: 47.
 30. Byrom B, Watson C, Doll H, et al. Selection of and evidentiary considerations for wearable devices and their measurements for use in regulatory decision making: recommendations from the ePRO consortium. *Value Health* 2018; 21: 631–639.
 31. Herrington WG, Goldsack JC and Landray MJ. Increasing the use of mobile technology-derived endpoints in clinical trials. *Clin Trials* 2018; 15: 313–315.
 32. Perry B, Geoghegan C, Lin L, et al. Patient preferences for using mobile technologies in clinical trials. *Contemp Clin Trials Commun* 2019; 15: 100399.
 33. Maas BR, Speelberg DHB, de Vries G-J, et al. Patient experience and feasibility of a remote monitoring system in Parkinson's disease. *Mov Disord Clin Pract* 2024; 11: 1223–1231.
 34. Moore K, O'Shea E, Kenny L, et al. Older Adults' experiences with using wearable devices: qualitative systematic review and meta-synthesis. *JMIR mHealth uHealth* 2021; 9: e23832.
 35. Bódi N, Kéri S, Nagy H, et al. Reward-learning and the novelty-seeking personality: a between- and within-subjects study of the effects of dopamine agonists on young Parkinson's patients. *Brain* 2009; 132: 2385–2395.
 36. Murphy R, Tubridy N, Kevelighan H, et al. Parkinson's disease: how is employment affected? *Ir J Med Sci* 2013; 182: 415–419.
 37. Callhoff J, Thiele K, Dörner T, et al. Trends in employment and hospitalisation in patients with Sjögren's syndrome 1996–2016: results from the German national database. *Clin Exp Rheumatol* 2019; 37: 83–89.
 38. Nicosia J, Aschenbrenner AJ, Adams SL, et al. Bridging the technological divide: stigmas and challenges with technology in digital brain health studies of older adults. *Front Digit Health* 2022; 4: 880055.
 39. Gordon NP and Crouch E. Digital information technology use and patient preferences for internet-based health education modalities: cross-sectional survey study of middle-aged and older adults with chronic health conditions. *JMIR Aging* 2019; 2: e12243.
 40. Han H-R. Integration of digital technology in research involving older adults: lessons from community-based trials. *Innov Aging* 2022; 6: 207–207.
 41. Miller DP, Weaver KE, Case LD, et al. Usability of a novel Mobile health iPad app by vulnerable populations. *JMIR MHealth UHealth* 2017; 5: e7268.
 42. Rai A, Chen L, Pye J, et al. Understanding determinants of consumer mobile health usage intentions, assimilation, and channel preferences. *J Med Internet Res* 2013; 15: e149.
 43. Zainal A, Aziz NFA, Ahmad NA, et al. Usability measures used to enhance user experience in using digital health technology among elderly: a systematic review. *Bull Electr Eng Inform* 2023; 12: 1825–1832.
 44. Zarghom S, Di Fonzo D and Leung F-H. Does socioeconomic Status affect Patients' ease of use of a touch-screen (iPad) patient survey? *Interact J Med Res* 2013; 2: e1.
 45. Zin KSLT, Kim S, Kim H-S, et al. A study on technology acceptance of digital healthcare among older Korean adults using extended tam (extended technology acceptance model). *Adm Sci* 2023; 13: 42.

46. Lobato L, Bethony JM, Pereira FB, et al. Impact of gender on the decision to participate in a clinical trial: a cross-sectional study. *BMC Public Health* 2014; 14: 1156.
47. Hawke LJ, Nelson E, O'Brien P, et al. Influences on clinical trial participation: enhancing recruitment through a gender lens – A scoping review. *Contemp Clin Trials Commun* 2024; 38: 101283.
48. Wilkowska W, Offermann-van Heek J, Laurentius T, et al. Insights into the older adults' world: concepts of aging, care, and using assistive technology in late adulthood. *Front Public Health* 2021; 9: 653931.
49. *Women in focus: understanding women as digital health consumers*, <https://rockhealth.com/insights/women-in-focus-understanding-women-as-digital-health-consumers/> (2025, accessed 8 September 2025).