



**Acceptance for Use of Sensitive Data
to extract Digital Biomarkers (DMs)**

A study developed under 'Validating DIGital Biomarkers for better personalized treatment of Parkinson's Disease' (DIGIPD) project

Framework Programme: Joint Transnational ERAPEMED 2020

**“MULTIDISCIPLINARY RESEARCH PROJECTS ON PERSONALISED
MEDICINE – PRE-/CLINICAL RESEARCH, BIG DATA AND ICT,
IMPLEMENTATION AND USER’S PERSPECTIVE”**

Coordinator of WP5: University of Namur (UN)

Sub-contractor for Task 5.4: Asociación Parkinson Madrid (APM)

Study centers: Asociación Parkinson Madrid – APM (Spain), Clinical Research Centre of the Brain and Spine Institute – ICM (France) and University Hospital Erlangen- UKE (Germany).

1. INTRODUCTION AND JUSTIFICATION OF THE STUDY

There is an urgent need to increase the efficiency and sustainability of health and social care systems across Europe. Public spending on health in Europe grew steadily before the global financial crisis. During the crisis there was a significant shift away from public spending on health, which was not reversed in the post-crisis period. Health systems were not as well equipped to meet the challenges posed by COVID-19 as they might have been in the absence of austerity¹. To avoid the mistakes of the past, governments will need to invest more publicly in health now and in the years ahead – even if they face growing budgetary pressure – to address the backlog created by disruption to health services, mitigate the negative health effects of foregone care, unemployment and strengthen preparedness for future shocks². At the same time, we are facing sociodemographic changes. Ageing of the population, accompanied by an increase in chronic diseases, including cardiovascular diseases, diabetes, asthma, mental and physical disorders, and neurodegenerative conditions is a reality³. The existence of comorbidities and the confluence of several chronic diseases are increasingly frequent in the elderly, which forces the need to develop models and tools to improve integrated health care systems.

The ageing of the population has also led to major reforms in long-term care policy and systems in many EU countries, increasing the need for alternatives. This implies the need for help with household tasks or other practical errands, transport to doctors or social visits, social companionship, emotional guidance or help in organizing professional care⁴. In most European countries, much of the care that people over 60 receive is informal care.

Among the most common chronic diseases in the elderly, dementia, Alzheimer and Parkinson are the most disabling ones, creating a strong impact on the quality of life of affected people and their families, and influencing the treatment of other chronic and overlapping diseases. Almost 10 million Europeans live with Parkinson, Alzheimer or other dementias today.

All these situations can be improved by the creation of an integrated care platform, capable of establishing correlations between co-morbidities, investigating the use of polypharmacy, mitigating

¹ Spending on health in Europe: entering a new era. World Health Organization 2021.

² Healthcare expenditure statistics. Current healthcare expenditure relative to GDP. Eurostat Statistics Explained. 2018.

³ Managing chronic conditions. Experience in eight countries. Ellen Nolte, Cécile Knai and Martin McKee. European Observatory on Health Systems and Policies. 2008.

⁴ Broese van Groenou, M.I., De Boer, A (2016) Providing informal care in a changing society. Eur J Ageing (13), doi: 10.1007/s10433-016- 0370-7.

potential health risks, studying the social variables involved and promoting unified treatment procedures or social services. This solution could help patients, caregivers and social health professionals to control several diseases, also considering the social context. In addition, people suffering from chronic diseases experience difficulties in their daily lives and require specialized care services as well as treatments. This situation imposes high burdens on the public budget, which require special attention in order to adequately address the sustainability of the social health system in Europe.

The main contribution of the DIGIPD project is to assess the extent to which DMs extracted from a mobile gait sensor system, as well as voice and face movement recordings, could help to make an accurate disease diagnosis and treatment-dependent prognosis for each patient. This could help make better informed medical decisions for each patient at the right time.

To achieve this, our main objective in this study, which corresponds to task 5.4 of WP5 - Analyzing the legal, ethical and social implications of the project/enabling GDPR compliant data access and management - is to investigate the acceptance of the use of sensitive personal data (specifically DMs) by patients for AI driven personalized medicine.

2. OBJECTIVES

Primary objective:

- To **collect** detailed information on the **opinions, thoughts, experiences and feelings** of users (people affected by PD) on the use of **digital biomarkers** (extracted from mobile gait sensors, voice recordings and face movements) in **clinical routine**.

Secondary objective:

- To **identify** those other factors that the DIGIPD system must take into account in order to gain **patient acceptance** and meet **patient demands**.

3. METHODOLOGY

3.1 Study design and duration

Study duration: 6 months (May 2022 – October 2022)

A transversal, qualitative and quantitative study was conducted over the same period of time in 3 different European Countries: France, Germany and Spain.

The total sample of patients was **333 people**. Their opinion was collected through different modalities of interaction such as telematic, face to face interviews and online survey.

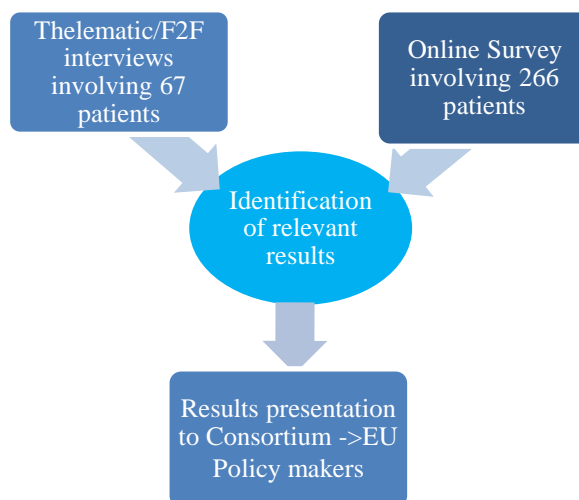


Figure 1 - Mixed methods study design

While quantitative research methods were used to provide general facts about a certain topic, qualitative research methods were more important for in-depth knowledge about experiences and ideas of end-users regarding healthcare issues⁵, and it has also been used as a method to engage patients and stakeholders in the health research⁶. Using a mixed methods design allows the study to yield rich and comprehensive data which can better reflect the participants' point of view⁷, and hence, ensures the end-users involvement in the project as a Use-Centered Design (UCD) approach key principle (see Figure 1).

During the methodological process all centers involved followed the same protocols (see attached annexes) when carrying out the interviews and the online survey with patients, with the analysis of results being centralized by Asociación Parkinson Madrid (APM).

The following table shows the Gantt Chart of the study over time together with the distribution of activities among the different members of the consortium:

| Consortium Member | Acceptance for the Use of Sensible Data Study | TIMELINE | | | |
|-------------------|--|--------------------|--|--|--|
| UN, APM | A1. Study protocol (co-creation of guidelines, questions, data collection/analysis templates, links to EU platform) | July 21– Apr 22 | | | |

5 Patton M, Cochran M.A guide to using qualitative research methodology. Médecins Sans Frontiers; 2002. URL: http://evaluation.msf.org/sites/evaluation/files/a_guide_to_using_qualitative_research_methodology.pdf. [accessed March 6, 2020].

6 Rolfe D E, Ramsden V R, Banner D. et al. Using qualitative Health Research methods to improve patient and public involvement and engagement in research. Res Involve Engagem. 2018; 4(1):1-8. doi.org/10.1186/s40900-018-0129-8

7 Wisdom J and Creswell JW. Mixed methods: Integrating quantitative and qualitative data collection and analysis while studying patient-centred medical home models. Rockville, MD. 2013. Agency for Healthcare Research and Quality. AHRQ Publication No. 13-0028-EF.

URL:https://pcmh.ahrq.gov/sites/default/files/attachments/MixedMethods_032513comp.pdf

| | | | | | |
|------------------------|--------------------------|--|-----------------------|-------------------|-----------|
| APM, ICM, UKE | A2. Data collection | | May 22 - Oct 22 | | |
| APM, (UN) | A3. Data analysis | | | Oct- Nov 22 | |
| APM, (UN, ICM, UKE) | A4. Results presentation | | | | Nov 22 |

Table 1 – Gantt chart: Acceptance for the Use of Sensible Data study

Information on the final distribution of the Data Collection activity among partners and the figures we achieved through the different modalities are indicated in Table 2, below:

| Consortium Member | interviews | Online surveys | TOTAL Patients |
|-------------------|------------|----------------|----------------|
| APM | 20 | 194 (+36) | 250 |
| ICM | 20 | 36 | 56 |
| UKE | 27 | 0 | 27 |
| TOTAL | 67 | 266 | 333 |

Table 2 – Data collection distribution among DIGIPD Consortium members

The following criteria was followed to carry out the distribution among the different members of the consortium:

- The previous effort agreed by each member of the consortium within this work task.
- The skills, experience and ambition that the consortium members described in their agreement.
- A wide representation of the countries involved in DIGIPD project: France, Germany and Spain.

3.2 Selection of participants

To reach our sample, we used different channels: databases of the participating organizations; national patient associations; social networks (e.g., Twitter; Facebook; LinkedIn; Google+); communication channels (e.g., partner magazines) and also DIGIPD social networks (e.g., <https://www.digipd.eu/>).

As for the selection process, the steps we followed were:

- A member of DIGIPD's team got in touch with those patients who have shown interest in participating in the research projects or who were regular contacts of the entity.
- People received information about the project either by phone or by e-mail.
- Participants who met the inclusion criteria were asked if they were interested in participating in the study and this participation took place within the set timeframe (months of May to October 2022).
- Interested participants received the fact sheet and signed the informed consent. Informed consent was given by the principal investigator or a member of the research team who had been trained in obtaining informed consent and who had been delegated this responsibility.

- It was the research staff of the study, trained in the interviews to be carried out, who conducted these meetings and subsequently transcribed the answers for the analysis.

3.3 Inclusion/exclusion criteria

Patients

Inclusion criteria

- Previous clinical diagnosis of Parkinson's.
- Willing to participate in the study by conducting the telematic interview/online survey.
- Who can give their written informed consent (if applicable from the guardian).

Exclusion criteria

- Patients with significant cognitive impairment, intellectual disability or other serious psychiatric conditions that may compromise their ability to answer/complete the telematic interview or online survey.

4. EXPECTED RESULTS AND LIMITATIONS

In terms of expected results, we expect that the knowledge gained from this study will help DIGIPD research team to understand the acceptance from patients of the use of their sensitive data and also other aspects that could be relevant for the user experience and satisfaction of participants.

On the other hand, as in most studies, prior to its implementation we had in mind possible limitations, some of which could be:

- Access limited to participants: in our initial design we envisaged a study sample of 180 participants with a proportional distribution between each of the study centers. However, and due to the health measures taken because of the Covid-19 crisis, some entities saw their access to the sample restricted. To compensate for this difficulty, telephone and telematic channels were considered by the DIGIPD consortium, so that we finally exceed the figure by far, reaching 333 participants.
- Sample/selection bias: due to the fact that the Spanish study center has a high media activity on social networks, the number of participants from Spain and other Spanish-speaking countries was higher than the number of French and German participants.
- Limitations arising from the methodological techniques used: through the interviews we further defined those answers obtained from the online survey and thanks to the high number of responses obtained through the online survey, the results can be considered more significant.

5. STATISTICAL ANALYSIS

A sample of convenience of 333 people was used.

Qualitative analysis

Researchers from the centers involved in the study transcribed and further translated the collected data from interviews into English. Transcription templates were provided using Excel sheets (see Annex 2. Section 1.4), and were available for all involved partners. The analysis process was done by researchers from APM following the thematic analysis approach⁸⁹, which involves 6 phases:

- i) Familiarization with the data, which considered reading the data and further organizing it considering the target groups and the questions' categories;
- ii) Acquiring identification codes;
- iii) Combining codes to generate different themes;
- iv) Reviewing themes in order to identify the recurrent themes (this phase also involved recreating, rearranging, or combining different themes together aiming to make sense out of the data in relation to the research questions);
- v) Defining and naming the themes, which included checking the literature and relating the findings to other studies;
- vi) Finally, finalizing the results with explanation of the meaning and significance of the results along with reporting about the whole process of analysis.

We took the time to examine the qualitative data in order to contextualize and enrich the quantitative data obtained with the online survey to tell a more holistic and accessible story about the opinions of users based on their everyday needs, than the numbers alone.

In this regard, we draw attention to the responses of some respondents and expressed the ideas of some of them, rather than trying to quantify our qualitative data, by weaving our quantitative and qualitative data into an integrated story.

Quantitative analysis

Quantitative analysis was descriptive and carried out with IBM SPSS Statistics Visor. The results were validated by a comparison of qualitative and quantitative data:

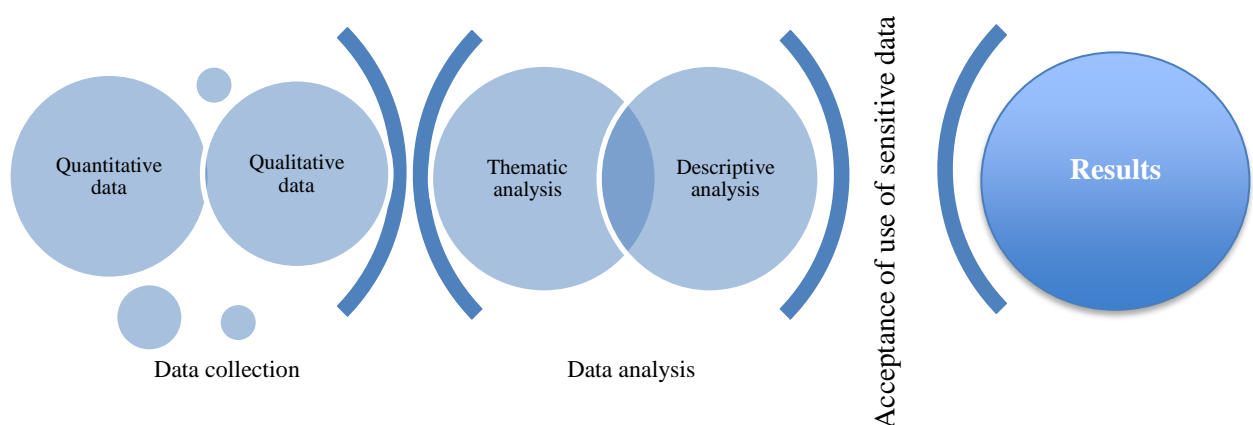


Figure 2 - Process of assessing acceptance of use of sensitive data

8 Boyatzis RE. Transforming qualitative information: Thematic analysis and code development. 1st edition. Sage publication; 1998. ISBN 13: 978-0761909613

9 Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol. 2006 ;3(2) :77-101. Doi :10.1191/1478088706qp063oa

6. ETHICAL CONSIDERATIONS

6.1 Data handling and record keeping

The information was handled confidentially in order to prevent participant names or other directly identifiable information from appearing in any report, publication or other disclosure of study results. Data on each individual - name, age, length of illness - was collected and stored in separate folders. The interviewers entered the pseudonymous data into a database for statistical analysis. Essential documents were archived in such a way as to ensure that they were readily available, on request, to the competent authorities.

The data obtained will be used only for the purposes of this research and will not be used for other purposes. The results of the research will be shared more widely, for example through publications and conferences. Personal information about the participants will never be displayed. The processing, communication and transfer of personal data will be carried out in accordance with the provisions of Regulation (EU) 2016/679 and Law 3/2018 of 5 December on the Protection of Personal Data and the Guarantee of Digital Rights. In accordance with the aforementioned legislation, the participant may exercise his/her rights of cancellation, opposition, portability, limitation, access and rectification by contacting the professional who informs them about this project. Likewise, we adhere to the principles of the GDPR (legality, equity and transparency; purpose limitation; minimization of data; accuracy; storage limitation; integrity and confidentiality; responsibility).

6.2 Subject's informed consent

Once the study had been fully explained to the subject, written informed consent was obtained prior to any study related procedure. The method for obtaining and documenting informed consent and the content of the consent was in accordance with Good Clinical Practice (GCP) and ICH (International Conference on Harmonization) standards, all applicable regulatory requirements and the legal requirements. The informed consent form to be used in this study, and any changes made during the course of the study, were prospectively approved by both the IRB/IEC prior to use.

The interviewer ensured that each patient, or his or her legally acceptable representative, was fully informed about the content, objectives, duration, procedures, voluntariness and possible risks of participation in the survey/interview. Any questions were considered and answered. At the end, they were given time to reflect if necessary, or if they requested more time.

If the subject accepted to participate in the study, he/she signed two copies of the informed consent form; one was given to the participant and the other was kept at the study site. The copy for the site was kept at the study site in a separate folder at the principal interviewer's office, but not in the participant's medical/social record.

The interviewer ensured that the enrolled subjects' current questions and concerns were adequately addressed, and informed the subjects of any new information that may affect their decision to continue to participate in the research study. Each interviewing center had a telephone number and email contact that was provided to study participants. In the event of substantial changes to the study, the interviewer should ask the subject for new consent to continue participation in the study. It was emphasized that the patient was free to withdraw his or her consent to participate at any time, without penalty or loss of benefits to which he or she is otherwise entitled. Patients who

refused to give or withdraw their written informed consent were not included or continued in this study, and this did not affect their subsequent care.

6.3 Security and adverse event reporting

There were no direct physical risks for any of the participants in these interviews and online surveys. There was a small risk of personal data theft; however, the DIGIPD consortium received advice from professionals in the field of data management and protection and took all possible precautions to mitigate this risk, including encryption and secure storage.

6.4 Withdrawal of participants

Participation in this study was entirely voluntary. Subjects could have withdrawn from the study at any time, without giving reasons and without disadvantage in terms of the quality of care they would have received if they did not participate.

After the withdrawal, no further data would have been collected or taken into consideration for statistical purposes.

7. RESULTS

Dates:

Participation period was from 17/05/2022 to 12/10/2022.

Figures:

Total: **333 participants**

- German: 27 paper interviews. Total of **27 German participants**.
- French: 36 online survey + 20 phone interviews. Total of **56 French participants**.
- Spanish: 20 face to face interviews + 194 online surveys from Spain + 36 online surveys from other Spanish speaking countries. Total of **250 Spanish participants**.

Recruitment process:





The recruitment process was similar in all three centres. Patients with PD through the data bases and networks were identified and contacted (*see Section 3.2 Selection of Participants*).

After an initial exchange during which the study, its description and purpose were explained to them, the informed consent form with the overall description in writing of the study was given in order to allow time for reflection and further exchanges to answer any questions they might have. Depending on the patients' preferences or requirements, the questions were then submitted to them in person onsite, by telephone or online.

SOCIODEMOGRAPHIC INFORMATION

Country

1.1 Which country are you living?

| | | Answers | Ratio |
|-----------|---|---------|---------|
| France |  | 56 | 16.82 % |
| Germany |  | 27 | 8.11 % |
| Spain |  | 214 | 64.26 % |
| Other |  | 36 | 10.81 % |
| No Answer | | 0 | 0 % |

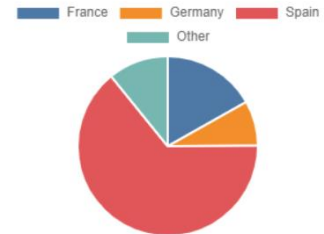






Figure 1

- **64% of participants were from Spain**, followed by 16.82% from *France* and 8.11% from *Germany*.
- 10.81% of participants who fall under *Other's* category filled out the questionnaire in the Spanish version so we consider that they were from other Spanish speaking countries. This is probably due to the fact that APM also reaches other Spanish-speaking countries in South America through social networks, mainly from Mexico, Argentina and Peru.

Age

1.2 What is your age?

| | | Answers | Ratio |
|-----------|---|---------|---------|
| Under 65 |  | 162 | 48.65 % |
| 65-75 |  | 108 | 32.43 % |
| 76-85 |  | 57 | 17.12 % |
| Over 85 |  | 5 | 1.5 % |
| No Answer | | 1 | 0.3 % |

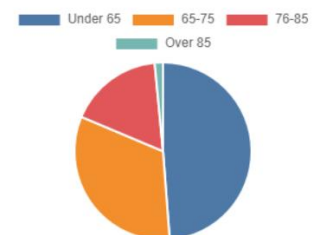




Figure 2

- **48.65% of participants were under 65 years of age** followed by 32.43% in the *65-75 age* range. The figure for those aged *76 and over* was much lower (17.12%), and even lower those aged *85 and over* (1.5%). In the latter case, they came from Spain and other Spanish-speaking countries.

At older ages we assume that there is a greater deterioration of health caused by PD and other comorbidities that may lead people to participate less in opinion polls and interviews. This, together with the fact that digital skills tend to be lower, may have been the reasons behind these percentages.

Gender

1.3 Which is your gender?

| | | Answers | Ratio |
|-----------|---|---------|---------|
| Male |  | 221 | 66.37 % |
| Female |  | 110 | 33.03 % |
| Intersex | | 0 | 0 % |
| No Answer | | 2 | 0.6 % |

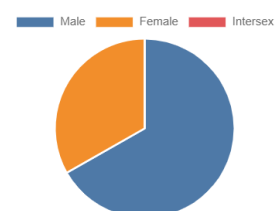


Figure 3

- Almost **twice as many men (66.37%)** as **women (33.03%)** with Parkinson's disease participated in the study.

This might have been due to several reasons. On the one hand, we are aware that more men than woman are diagnosed with PD by a ratio of approximately 2:1¹⁰¹¹. On the other hand, from a certain age onwards, there is a greater digital divide in access to and abilities to use technological devices that would be required in the case of completing the survey online. This gap is even greater among women who, on many occasions, have had fewer opportunities to interact with technology during their working years due to the type of work they did and therefore fewer opportunities to learn.

Academic education

32.73% of participants had post-secondary school studies, followed closely by participants with master's degree (30.93%) and secondary school (15.62%), with a considerable 12.01% participants with PhD's degree.

This could be due to the fact that a high level of education might lead to a higher level of involvement in activities such as studies or completing online surveys.

1.4 Which is your highest academic education?

| | Answers | Ratio |
|-----------------------|---------|---------|
| PhD's degree | 40 | 12.01 % |
| Master degree | 103 | 30.93 % |
| Post-secondary school | 109 | 32.73 % |
| Secondary school | 52 | 15.62 % |
| Primary school | 19 | 5.71 % |
| No formal education | 10 | 3 % |
| No Answer | 0 | 0 % |

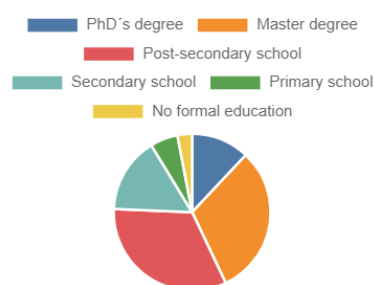


Figure 3

- Per country: 50% of *French* participants had post-secondary education followed by a 32.14% with master's degree. *German* participants with a master's degree (37.04%) or secondary school (37.04%) were the majority. 30.84% of participants from *Spain* had post-secondary education closely followed by people with master's degree (28.50%). The majority of participants from *other Spanish-speaking countries* had a master's degree (38.89%), followed closely by participants with post-secondary education (33.33%).
- Per age: Participants *under 65* had mainly post-secondary (35.80%) and master's degree (34.57%) studies. To a lesser extent their education was secondary school 14.81%. Most of the participants in *65-75 age* group had master's degree (31.48%) and post-secondary (29.63%) education. *76-85 years old* subjects had mainly post-secondary (26.32%), master's degree (21.05%), primary (19.30%) and secondary school education (17.54%). More than half of the participants *over 85* had post-secondary education (60%). Within this age group also participants with master's degree (20%) and primary school studies (20%) participated.

10 Bordelon Y, Fahn S. Gender differences in movement disorders. In: Kaplan P, editor. Neurologic disease in women. Demos; New York: 2006.

11 Van Den Eeden SK, Tanner CM, Bernstein AL, et al. Incidence of Parkinson's disease: variation by age, gender, and race/ethnicity. Am J Epidemiol. 2003;157(11):1015–1022.

- Per gender: Most of *female* participants had master's degree (31.82%) and post-secondary (29.09%). The *male* participants in this study had mostly post-secondary (34.84%) and master's degree (30.77%) education.

| 1.4 Which is your highest academic education? | France | % | Germany | % | Spain | % | Other | % |
|---|-----------|----------------|-----------|----------------|------------|----------------|-----------|----------------|
| Post-secondary school | 28 | 50,00% | 3 | 11,11% | 66 | 30,84% | 12 | 33,33% |
| Master degree | 18 | 32,14% | 10 | 37,04% | 61 | 28,50% | 14 | 38,89% |
| Secondary school | 4 | 7,14% | 10 | 37,04% | 33 | 15,42% | 5 | 13,89% |
| PhD's degree | 6 | 10,71% | 2 | 7,41% | 29 | 13,55% | 3 | 8,33% |
| Primary school | 0 | 0,00% | 0 | 0,00% | 19 | 8,88% | 0 | 0,00% |
| No formal education | 0 | 0,00% | 2 | 7,41% | 6 | 2,80% | 2 | 5,56% |
| TOTAL | 56 | 100,00% | 27 | 100,00% | 214 | 100,00% | 36 | 100,00% |

Table 1 – Academic education per country

| 1.4 Which is your highest academic education? | Under 65 | % | 65-75 | % | 76-85 | % | Over 85 | % |
|---|------------|----------------|------------|----------------|-----------|----------------|----------|----------------|
| Post-secondary school | 58 | 35,80% | 32 | 29,63% | 15 | 26,32% | 3 | 60,00% |
| Master degree | 56 | 34,57% | 34 | 31,48% | 12 | 21,05% | 1 | 20,00% |
| Secondary school | 24 | 14,81% | 18 | 16,67% | 10 | 17,54% | 0 | 0,00% |
| PhD's degree | 17 | 10,49% | 16 | 14,81% | 7 | 12,28% | 0 | 0,00% |
| Primary school | 4 | 2,47% | 3 | 2,78% | 11 | 19,30% | 1 | 20,00% |
| No formal education | 3 | 1,85% | 5 | 4,63% | 2 | 3,51% | 0 | 0,00% |
| TOTAL | 162 | 100,00% | 108 | 100,00% | 57 | 100,00% | 5 | 100,00% |

Table 2 – Academic education per age

| 1.4 Which is your highest academic education? | Female | % | Male | % |
|---|------------|----------------|------------|----------------|
| Post-secondary school | 32 | 29,09% | 77 | 34,84% |
| Master degree | 35 | 31,82% | 68 | 30,77% |
| Secondary school | 20 | 18,18% | 31 | 14,03% |
| PhD's degree | 12 | 10,91% | 27 | 12,22% |
| Primary school | 8 | 7,27% | 11 | 4,98% |
| No formal education | 3 | 2,73% | 7 | 3,17% |
| TOTAL | 110 | 100,00% | 221 | 100,00% |

Table 3 – Academic education per gender

Diagnose

1.5 What is your main diagnose?

| | Answers | Ratio |
|---------------------|---------|---------|
| Parkinson's disease | 316 | 94.89 % |
| Other | 14 | 4.2 % |
| No Answer | 6 | 1.8 % |

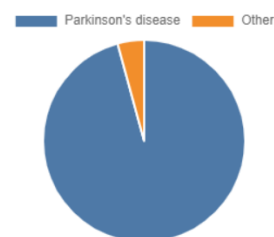


Figure 4

- 94.89%** of participants indicated that they had a possible diagnosis of **Parkinson's disease**.

Time since diagnosis

In terms of the length of time since the diagnosis, **42.65% of participants were in the range between 1-5 years since diagnosis**, followed by 32.73% of participants who had been diagnosed between 6-10 years. At a significant distance there were participants who had been diagnosed between 11-15 years ago (11.71%), 16-20 years (3.33%) and over 20 years (3%).

1.6 How long has it been since your diagnosis?

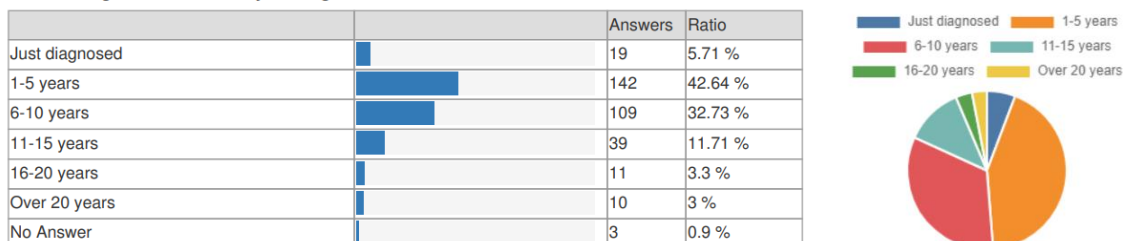


Figure 5

- This percentage remained practically the same in the different countries under different genders and different academic studies.
- Participants over 85 group was the group that had been diagnosed longer ago: 40% received diagnosed 11-15 years ago followed by those who receive it 1-5 years or 6-10 years ago.

| 1.6 How long has it been since your diagnosis | France | % | Germany | % | Spain | % | Other | % |
|---|-----------|----------------|-----------|----------------|------------|----------------|-----------|----------------|
| Just diagnosed | 2 | 3,57% | 0 | 0,00% | 16 | 7,48% | 1 | 2,78% |
| 1-5 years | 26 | 46,43% | 13 | 48,15% | 89 | 41,59% | 13 | 36,11% |
| 6-10 years | 25 | 44,64% | 9 | 33,33% | 59 | 27,57% | 15 | 41,67% |
| 11-15 years | 0 | 0,00% | 2 | 7,41% | 33 | 15,42% | 4 | 11,11% |
| 16-20 years | 2 | 3,57% | 1 | 3,70% | 8 | 3,74% | 1 | 2,78% |
| Over 20 years | 1 | 1,79% | 2 | 7,41% | 6 | 2,80% | 2 | 5,56% |
| No answer | 0 | 0,00% | 0 | 0,00% | 3 | 1,40% | 0 | 0,00% |
| TOTAL | 56 | 100,00% | 27 | 100,00% | 214 | 100,00% | 36 | 100,00% |

Table 4 - Time since diagnosis per country

| 1.6 How long has it been since your diagnosis | Female | % | Male | % |
|---|------------|----------------|------------|----------------|
| Just diagnosed | 6 | 5,45% | 13 | 5,88% |
| 1-5 years | 54 | 49,09% | 87 | 39,37% |
| 6-10 years | 30 | 27,27% | 78 | 35,29% |
| 11-15 years | 11 | 10,00% | 28 | 12,67% |
| 16-20 years | 4 | 3,64% | 7 | 3,17% |
| Over 20 years | 3 | 2,73% | 7 | 3,17% |
| No answer | 2 | 1,82% | 1 | 0,45% |
| TOTAL | 110 | 100,00% | 221 | 100,00% |

Table 5 - Time since diagnosis per gender

| 1.6 How long has it been since your diagnosis | Under 65 | % | 65-75 | % | 76-85 | % | Over 85 | % |
|---|------------|----------------|------------|----------------|-----------|----------------|----------|----------------|
| Just diagnosed | 9 | 5,56% | 8 | 7,41% | 2 | 3,51% | 0 | 0,00% |
| 1-5 years | 68 | 41,98% | 46 | 42,59% | 27 | 47,37% | 1 | 20,00% |
| 6-10 years | 56 | 34,57% | 35 | 32,41% | 17 | 29,82% | 1 | 20,00% |
| 11-15 years | 18 | 11,11% | 14 | 12,96% | 5 | 8,77% | 2 | 40,00% |
| 16-20 years | 4 | 2,47% | 3 | 2,78% | 4 | 7,02% | 0 | 0,00% |
| Over 20 years | 5 | 3,09% | 2 | 1,85% | 2 | 3,51% | 0 | 0,00% |
| No answer | 2 | 1,23% | 0 | 0,00% | 0 | 0,00% | 1 | 20,00% |
| TOTAL | 162 | 100,00% | 108 | 100,00% | 57 | 100,00% | 5 | 100,00% |

Table 6 - Time since diagnosis per age

| 1.6 How long has it been since your diagnosis | No formal education | | Primary school | | Secondary school | | Post-secondary school | | Master degree | | PhD's degree | |
|---|---------------------|----------------|----------------|----------------|------------------|----------------|-----------------------|----------------|---------------|----------------|--------------|----------------|
| | | % | | % | | % | | % | | % | | % |
| Just diagnosed | 0 | 0,00% | 0 | 0,00% | 3 | 5,77% | 8 | 7,34% | 7 | 6,80% | 1 | 2,50% |
| 1-5 years | 6 | 60,00% | 6 | 31,58% | 25 | 48,08% | 43 | 39,45% | 46 | 44,66% | 16 | 40,00% |
| 6-10 years | 2 | 20,00% | 6 | 31,58% | 13 | 25,00% | 38 | 34,86% | 36 | 34,95% | 14 | 35,00% |
| 11-15 years | 1 | 10,00% | 5 | 26,32% | 7 | 13,46% | 14 | 12,84% | 7 | 6,80% | 5 | 12,50% |
| 16-20 years | 1 | 10,00% | 2 | 10,53% | 2 | 3,85% | 3 | 2,75% | 1 | 0,97% | 2 | 5,00% |
| Over 20 years | 0 | 0,00% | 0 | 0,00% | 1 | 1,92% | 2 | 1,83% | 5 | 4,85% | 2 | 5,00% |
| No answer | 0 | 0,00% | 0 | 0,00% | 1 | 1,92% | 1 | 0,92% | 1 | 0,97% | 0 | 0,00% |
| TOTAL | 10 | 100,00% | 19 | 100,00% | 52 | 100,00% | 109 | 100,00% | 103 | 100,00% | 40 | 100,00% |

Table 7 - Time since diagnosis per academic education

Caregiver

If we take into account the previous results, in which 75.78% of the participants had a maximum of 10 years since diagnosis, we see that it makes sense that their physical and cognitive state was not very deteriorated, having a high chance of continuing to be autonomous. This could be reflected in the fact that **69.37% of participants did not need a caregiver.**

1.7 Do you have a caregiver?

| | Answers | Ratio |
|---|---------|---------|
| No need a carer | 231 | 69.37 % |
| Informal carer (e.g. relative, neighbour, friend) | 83 | 24.92 % |
| Formal carer (e.g. support assistant, nurse) | 10 | 3 % |
| Other | 8 | 2.4 % |
| No Answer | 1 | 0.3 % |

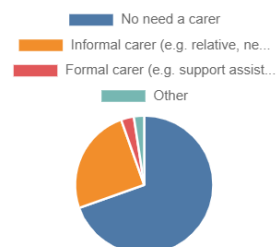


Figure 6

- Compared with other countries, a higher percentage of participants from *other Spanish speaking countries* needed an informal caregiver (44.44%). In *Spain*, 26.17% of participants said they needed one, the second higher figure.

This is in line with data from the Social Protection Committee (SPC) and the European Commission (DG EMPL)¹² which indicates that in 2016 Spain recorded the highest shares of people providing at least 20 hours of informal homecare services. In this country (Spain) based on data from INE's Survey (Institute of National Statistics) on the use of unpaid time¹³, and applying INE's own criteria on full-time jobs, there are 28 million full-time unpaid care jobs in the broadest sense, which is 30% more than the entire labour market.

¹² 2021 Long-Term Care Report. Trends, challenges and opportunities in an ageing society. Country Profiles. Volume II. Doi: 10.2767/183997

¹³ <https://www.ine.es/dynt3/inebase/index.htm?type=pcaxis&path=/t25/e447/a2009-2010/p01/&file=pcaxis&L=1>

- By age, from 76-85 onwards, we found more people who needed a carer than those who did not. 80% of people *over 85* manifested to need support from an informal caregiver.
- By gender, male participants reported the highest percentage of not needing a caregiver 72.85%. Females reported the highest attendance by informal caregivers (28.18%).
- Participants with *no formal education* were those that received the highest percentage of support from informal caregivers (60%). And participants with *PhD's degree* those that received the lowest percentage of support from them (15%). Regarding formal caregivers (e.g., nurses, support assistants), those participants with *primary school* studies were receiving the highest percentage of support from them (15.79%).

| 1.7 Do you have a caregiver? | France | % | Germany | % | Spain | % | Other | % |
|--|-----------|----------------|-----------|----------------|------------|----------------|-----------|----------------|
| No need a carer | 45 | 80,36% | 24 | 88,89% | 142 | 66,36% | 20 | 55,56% |
| Informal carer (e.g., relative, friend) | 9 | 16,07% | 2 | 7,41% | 56 | 26,17% | 16 | 44,44% |
| Formal carer (e.g. support assistant, nurse) | 2 | 3,57% | 0 | 0,00% | 8 | 3,74% | 0 | 0,00% |
| Other | 0 | 0,00% | 1 | 3,70% | 7 | 3,27% | 0 | 0,00% |
| No answer | 0 | 0,00% | 0 | 0,00% | 1 | 0,47% | 0 | 0,00% |
| TOTAL | 56 | 100,00% | 27 | 100,00% | 214 | 100,00% | 36 | 100,00% |

Table 8 - Caregiver per country

| 1.7 Do you have a caregiver? | Under 65 | % | 65-75 | % | 76-85 | % | Over 85 | % |
|--|------------|----------------|------------|----------------|-----------|----------------|----------|----------------|
| No need a carer | 128 | 79,01% | 79 | 73,15% | 23 | 40,35% | 1 | 20,00% |
| Informal carer (e.g., relative, friend) | 28 | 17,28% | 23 | 21,30% | 27 | 47,37% | 4 | 80,00% |
| Formal carer (e.g. support assistant, nurse) | 2 | 1,23% | 3 | 2,78% | 5 | 8,77% | 0 | 0,00% |
| Other | 3 | 1,85% | 3 | 2,78% | 2 | 3,51% | 0 | 0,00% |
| No answer | 1 | 0,62% | 0 | 0,00% | 0 | 0,00% | 0 | 0,00% |
| TOTAL | 162 | 100,00% | 108 | 100,00% | 57 | 100,00% | 5 | 100,00% |

Table 9 - Caregiver per age

| 1.7 Do you have a caregiver? | Female | % | Male | % |
|--|------------|----------------|------------|----------------|
| No need a carer | 69 | 62,73% | 161 | 72,85% |
| Informal carer (e.g., relative, friend) | 31 | 28,18% | 52 | 23,53% |
| Formal carer (e.g. support assistant, nurse) | 5 | 4,55% | 4 | 1,81% |
| Other | 5 | 4,55% | 3 | 1,36% |
| No answer | 0 | 0,00% | 1 | 0,45% |
| TOTAL | 110 | 100,00% | 221 | 100,00% |

Table 10 - Caregiver per gender

| 1.7 Do you have a caregiver? | No formal education | % | Primary school | % | Secondary school | % | Post-secondary school | % | Master degree | % | PhD's degree | % |
|--|---------------------|----------------|----------------|----------------|------------------|----------------|-----------------------|----------------|---------------|----------------|--------------|----------------|
| No need a carer | 4 | 40,00% | 5 | 26,32% | 39 | 75,00% | 75 | 68,81% | 77 | 74,76% | 31 | 77,50% |
| Informal carer (e.g., relative, friend) | 6 | 60,00% | 10 | 52,63% | 10 | 19,23% | 29 | 26,61% | 22 | 21,36% | 6 | 15,00% |
| Formal carer (e.g. support assistant, nurse) | 0 | 0,00% | 3 | 15,79% | 1 | 1,92% | 3 | 2,75% | 2 | 1,94% | 1 | 2,50% |
| Other | 0 | 0,00% | 1 | 5,26% | 2 | 3,85% | 2 | 1,83% | 2 | 1,94% | 1 | 2,50% |
| No answer | 0 | 0,00% | 0 | 0,00% | 0 | 0,00% | 0 | 0,00% | 0 | 0,00% | 1 | 2,50% |
| TOTAL | 10 | 100,00% | 19 | 100,00% | 52 | 100,00% | 109 | 100,00% | 103 | 100,00% | 40 | 100,00% |

Table 11 - Caregiver per academic education

Housing

In 2018, there were 101 million older people (aged 65 or over) living in the EU. Of these, most of them were living in predominantly urban regions, followed by intermediate regions and lastly rural regions. Most elderly people value their independence and would prefer to continue to live in their own homes and the overwhelming majority continue to live in private households (either alone, with their spouse or with other persons).

In this sense, in this study **97.9% of participants** reported to live in their **own home**. A minority of patients from *other Spanish speaking countries* reported to live at home and temporary in care (2.78%).

1.8 What type of housing do you live in?

| | Answers | Ratio |
|---|---------|--------|
| At home | 326 | 97.9 % |
| At home and temporary in care (e.g. day care) | 2 | 0.6 % |
| In residential care | 2 | 0.6 % |
| Other | 3 | 0.9 % |
| No Answer | 0 | 0 % |

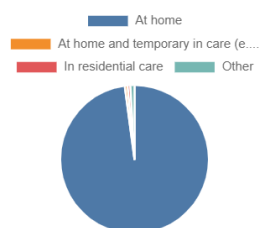


Figure 7

- There were no significant differences by gender or educational background. Only to mention that the 10% of participants with *no formal education* lived at home and temporary in care. This was the highest rate.

| 1.8 Type of housing | France | % | Germany | % | Spain | % | Other | % |
|-------------------------------|-----------|----------------|-----------|----------------|------------|----------------|-----------|----------------|
| At home | 56 | 100,00% | 27 | 100,00% | 209 | 97,66% | 34 | 94,44% |
| At home and temporary in care | 0 | 0,00% | 0 | 0,00% | 2 | 0,93% | 1 | 2,78% |
| In residential care | 0 | 0,00% | 0 | 0,00% | 2 | 0,93% | 0 | 0,00% |
| Other | 0 | 0,00% | 0 | 0,00% | 1 | 0,47% | 1 | 2,78% |
| TOTAL | 56 | 100,00% | 27 | 100,00% | 214 | 100,00% | 36 | 100,00% |

Table 12 – Housing per country

| 1.8 Type of housing | Under 65 | % | 65-75 | % | 76-85 | % | Over 85 | % |
|-------------------------------|------------|----------------|------------|----------------|-----------|----------------|----------|----------------|
| At home | 160 | 98,77% | 105 | 97,22% | 55 | 96,49% | 5 | 100,00% |
| At home and temporary in care | 1 | 0,62% | 2 | 1,85% | 0 | 0,00% | 0 | 0,00% |
| In residential care | 0 | 0,00% | 0 | 0,00% | 2 | 3,51% | 0 | 0,00% |
| Other | 1 | 0,62% | 1 | 0,93% | 0 | 0,00% | 0 | 0,00% |
| TOTAL | 162 | 100,00% | 108 | 100,00% | 57 | 100,00% | 5 | 100,00% |

Table 13 – Housing per age

| 1.8 Type of housing | Female | % | Male | % |
|-------------------------------|------------|----------------|------------|----------------|
| At home | 106 | 96,36% | 218 | 98,64% |
| At home and temporary in care | 3 | 2,73% | 2 | 0,90% |
| In residential care | 1 | 0,91% | 1 | 0,45% |
| Other | 0 | 0,00% | 0 | 0,00% |
| TOTAL | 110 | 100,00% | 221 | 100,00% |

Table 14 – Housing per gender

| 1.8 Type of housing | No formal education | | Primary school | | Secondary school | | Post-secondary school | | Master degree | | PhD's degree | |
|-------------------------------|---------------------|----------------|----------------|----------------|------------------|----------------|-----------------------|----------------|---------------|----------------|--------------|----------------|
| | | % | | % | | % | | % | | % | | % |
| At home | 9 | 90,00% | 17 | 89,47% | 50 | 96,15% | 107 | 98,17% | 103 | 100,00% | 40 | 100,00% |
| At home and temporary in care | 1 | 10,00% | 0 | 0,00% | 2 | 3,85% | 0 | 0,00% | 0 | 0,00% | 0 | 0,00% |
| In residential care | 0 | 0,00% | 2 | 10,53% | 0 | 0,00% | 0 | 0,00% | 0 | 0,00% | 0 | 0,00% |
| Other | 0 | 0,00% | 0 | 0,00% | 0 | 0,00% | 2 | 1,83% | 0 | 0,00% | 0 | 0,00% |
| TOTAL | 10 | 100,00% | 19 | 100,00% | 52 | 100,00% | 109 | 100,00% | 103 | 100,00% | 40 | 100,00% |

Table 15 – Housing per academic education

DEVICES AND PROCEDURES

Q1 - Use of Digital Devices

The Annual Community Survey on ICT usage in households and by individuals¹⁴ reveals that older people are currently closing the digital divide; nevertheless, they remain relatively slow to adopt new technologies.

In this study, although the 49.55% of participants indicated that they had never **used devices to monitor aspects of health**, the **47.75%** of people indicated that they had done so.

2.1 Have you ever used digital devices that collect process and/or display personal data to help you detect aspects of your health? (i.e., smartphone, tablet, computer, specific wearable device –gait sensor on a shoe)

| | Answers | Ratio |
|-------------|---------|---------|
| Yes | 159 | 47.75 % |
| No | 165 | 49.55 % |
| I am unsure | 8 | 2.4 % |
| No Answer | 1 | 0.3 % |

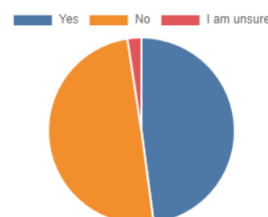


Figure 8

- *Spanish* participants *under 65* were those that rated the highest in the use of digital health care devices (63.4%) followed by *Spanish* participants between *76-85 years* old (60.9%) and *French* participants also that range of age (30.4%).
- Half of people *under 65* (50.62%) and *between 65-75* (50%) had already used digital health devices. In *76-85* age group we found more people who had not use digital health devices (56.14%) and *Over 85*, the total number of participants had never use digital devices for health (100%).
- By gender, 52.73% of *females* had used digital devices, a slightly higher percentage than men (50.68%). The men who had used them the most were in the 65-75 age group.
- By educational studies, participants with *non-formal education* were the least likely to use digital health devices (30%) being those with *PhD's degree* the most likely (55%).

14

https://ec.europa.eu/eurostat/statisticsexplained/index.php?title=Glossary:Community_survey_on_ICT_usage_in_households_and_by_individuals

| 2.1 Use of digital devices for health | Under 65 | % | 65-75 | % | 76-85 | % | Over 85 | % |
|---------------------------------------|------------|----------------|------------|----------------|-----------|----------------|----------|----------------|
| Yes | 82 | 50,62% | 54 | 50,00% | 23 | 40,35% | 0 | 0,00% |
| No | 78 | 48,15% | 49 | 45,37% | 32 | 56,14% | 5 | 100,00% |
| Unsure | 1 | 0,62% | 5 | 4,63% | 2 | 3,51% | 0 | 0,00% |
| Other | 1 | 0,62% | 0 | 0,00% | 0 | 0,00% | 0 | 0,00% |
| TOTAL | 162 | 100,00% | 108 | 100,00% | 57 | 100,00% | 5 | 100,00% |

Table 16 – Use of digital devices per age

| 2.1 Use of digital devices for health | Female | % | Male | % |
|---------------------------------------|------------|----------------|------------|----------------|
| Yes | 58 | 52,73% | 101 | 45,70% |
| No | 51 | 46,36% | 112 | 50,68% |
| Unsure | 1 | 0,91% | 7 | 3,17% |
| Other | 0 | 0,00% | 1 | 0,45% |
| TOTAL | 110 | 100,00% | 221 | 100,00% |

Table 17 – Use of digital devices per gender

| 2.1 Use of digital devices for health | No formal education | % | Primary school | % | Secondary school | % | Post-secondary school | % | Master degree | % | PhD's degree | % |
|---------------------------------------|---------------------|----------------|----------------|----------------|------------------|----------------|-----------------------|----------------|---------------|----------------|--------------|----------------|
| Yes | 3 | 30,00% | 7 | 36,84% | 22 | 42,31% | 55 | 50,46% | 50 | 48,54% | 22 | 55,00% |
| No | 7 | 70,00% | 12 | 63,16% | 26 | 50,00% | 52 | 47,71% | 50 | 48,54% | 18 | 45,00% |
| Unsure | 0 | 0,00% | 0 | 0,00% | 3 | 5,77% | 2 | 1,83% | 3 | 2,91% | 0 | 0,00% |
| Other | 0 | 0,00% | 0 | 0,00% | 1 | 1,92% | 0 | 0,00% | 0 | 0,00% | 0 | 0,00% |
| TOTAL | 10 | 100,00% | 19 | 100,00% | 52 | 100,00% | 109 | 100,00% | 103 | 100,00% | 40 | 100,00% |

Table 18 – Use of digital devices per academic education

| | | COUNTRY | | | |
|-------------|----------|------------|------------|-------|-------|
| Q1 | AGE | Frecuencia | Porcentaje | | |
| I am unsure | Under 65 | France | 1 | 100,0 | |
| | | 65-75 | France | 1 | 20,0 |
| | | | Spain | 4 | 80,0 |
| | 76-85 | Total | 5 | 100,0 | |
| | | Other | 1 | 50,0 | |
| | | Spain | 1 | 50,0 | |
| | No | Under 65 | Total | 2 | 100,0 |
| | | | Other | 1 | 100,0 |
| | | | Spain | 1 | 100,0 |
| | | 65-75 | France | 11 | 22,4 |
| | | | Germany | 3 | 6,1 |
| | | | Other | 8 | 16,3 |
| | | | Spain | 27 | 55,1 |
| | | | Total | 49 | 100,0 |
| | | 76-85 | France | 2 | 6,3 |
| Germany | | | 2 | 6,3 | |
| Other | | | 2 | 6,3 | |
| Spain | | | 26 | 81,3 | |
| Total | | | 32 | 100,0 | |
| Over 85 | | Other | 2 | 40,0 | |
| | | Spain | 3 | 60,0 | |
| | Total | 5 | 100,0 | | |
| Yes | Under 65 | France | 9 | 11,5 | |
| | | Germany | 1 | 1,3 | |
| | | Other | 11 | 14,1 | |
| | | Spain | 57 | 73,1 | |
| | | Total | 78 | 100,0 | |
| | 65-75 | France | 13 | 24,1 | |
| | | Germany | 9 | 16,7 | |
| | | Other | 3 | 5,6 | |
| | | Spain | 29 | 53,7 | |
| | | Total | 54 | 100,0 | |
| 76-85 | France | 7 | 30,4 | | |
| | Germany | 2 | 8,7 | | |
| | Spain | 14 | 60,9 | | |
| | Total | 23 | 100,0 | | |
| | Under 65 | France | 12 | 14,6 | |
| Germany | | 10 | 12,2 | | |
| Other | | 8 | 9,8 | | |
| Spain | | 52 | 63,4 | | |
| Total | | 82 | 100,0 | | |

Table 19 – Use of digital devices per age and country

| | | GENDER | | | |
|-------------|----------|------------|------------|-------|-------|
| Q1 | AGE | Frecuencia | Porcentaje | | |
| I am unsure | Under 65 | Male | 1 | 100,0 | |
| | | 65-75 | Male | 5 | 100,0 |
| | 76-85 | | Female | 1 | 50,0 |
| | | Male | 1 | 50,0 | |
| | | Total | 2 | 100,0 | |
| | No | Under 65 | Male | 1 | 100,0 |
| | | | Female | 1 | 100,0 |
| | | 65-75 | Female | 1 | 2,0 |
| | | | Male | 17 | 34,7 |
| | | | Male | 31 | 63,3 |
| 76-85 | | Total | 49 | 100,0 | |
| | | Female | 13 | 40,6 | |
| | | Male | 19 | 59,4 | |
| Yes | | Over 85 | Total | 32 | 100,0 |
| | | | Female | 1 | 20,0 |
| | Male | | 4 | 80,0 | |
| | Under 65 | Total | 5 | 100,0 | |
| | | Female | 1 | 1,3 | |
| | | Male | 19 | 24,4 | |
| | | Male | 58 | 74,4 | |
| | | Total | 78 | 100,0 | |
| | 65-75 | Female | 17 | 31,5 | |
| | | Male | 37 | 68,5 | |
| Total | | 54 | 100,0 | | |
| 76-85 | | Female | 11 | 47,8 | |
| | | Male | 12 | 52,2 | |
| | Total | 23 | 100,0 | | |
| Under 65 | Female | 30 | 36,6 | | |
| | Male | 52 | 63,4 | | |
| | Total | 82 | 100,0 | | |

Table 20 – Use of digital devices per age and gender

During the interviews several participants told us:

- They regularly used their mobile phones to make calls, or send WhatsApp messages. They also used computers very often.
- Regarding the use of smartwatches connected to their mobile phones, they liked to see the steps/calories information (“*Interesting to force to move!*”). Also, reminders for medication intake.
- A significant percentage of participants in Spain had used hollers for the preparation of consultation with their neurologist (e.g., STAT-ON) and apps/sensors during races (in shoe and on the bib) to see their physical activity data.
- We also interviewed participants that had collaborated in studies on early detection of PD through the use of the computer. And some others, in European projects using a smart watch connected to the mobile phone and/or a camera placed in a room where they spent some time in order to collect health data and detect symptoms of their disease.
- As for other applications and software mentioned by the group of participants, we found the following:
 - Dragon software. Voice recognition software for dictation and transcription.
 - DIGIPARK App. Free App for Parkinson’s patients and their relatives that is divided in 3 parts: Pill box reminders, symptom diary records and voice dictation.
 - <https://www.seenovate.com> and <http://seesports.com> . To exploit and enhance information through visual and dynamic dashboards.

On what they told us about their experience using digital devices:

- “ *It is very positive and I am going to buy one smartwatch because it is very useful” .*
- “*I wear an e-watch because “I like technology a lot, I'm very ‘geeky’” .*
- “*I found it very interesting and appropriate to use this kind of digital devices” .*

Q2 - Willingness to Use Digital Devices

83.48% of participants indicated that they will be **willing to use digital devices** if this would improve the information that their health and social care teams had about their health.

2.2 Would you use digital devices (i.e., smartphone, tablet, computer, specific wearable device –gait sensor on a shoe) if this would improve the information that your health care team has about you?

| | Answers | Ratio |
|-------------|---------|---------|
| Yes | 278 | 83.48 % |
| No | 30 | 9.01 % |
| I am unsure | 22 | 6.61 % |
| No Answer | 3 | 0.9 % |

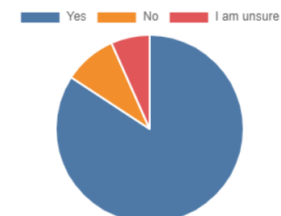


Figure 9

- Participants from *other Spanish* speaking countries (86.11%) showed one of the greater willingness to use this type of devices together with participants from *Spain* (85.51%) and from *Germany* (81.48%).

- Participants *under 65* were the most likely to use digital devices for health purposes (89.51%) and those who had less doubts to do so (3.70%). Participants between *65-75* years, were also highly willing to use digital devices (80.56%) although there was an increase in those who indicated that they would not use them (9.26%) and also in those who had doubts (9.26%).

As the age range increased, the percentages continued to evolve in the same way: decreasing willingness and increasing doubts. This way, participants *over 85* were the least likely to use digital devices for health purposes (100%).

- Regarding gender: Older men tend to have a more open attitude to the digital technologies than older women, this may be linked to older men having been more exposed to new technologies in the workplace (either due to their choice of occupation or simply because a higher proportion of men than women work). These differences between the sexes may explain, at least in part, why the use of ICTs falls away for very old people (a development that is magnified due to women accounting for a much larger share of survivors within this age category). By contrast, there is little evidence of a digital divide between the sexes among younger generations, for example, almost all young men and women make use of the internet on a daily basis.

In this study, 84.62% of *male participants* indicated that they would do such a use. Those were mostly from Spain (66.80%), under 65 (53.5%) and with Master's Degree (33.70%). A higher percentage than for *females* (80.91%). Males also indicated to a less extent that they would not use them (8.60%) and were the less hesitant group (5.88%).

- As for educational studies, participants with *non-formal education* where those that indicated the least willingness to use this type of devices (60%) and who said in a higher percentage (30%) that would not do so. The *Master's degree* group was the most likely to use digital devices for this purpose (90.29%); they showed the least negative attitude (5.83%), and said to have the fewest doubts (3.88%).

| 2.2 Use digital devices if information health team improved | | | | | | | | |
|---|-----------|----------------|-----------|----------------|------------|----------------|-----------|----------------|
| | France | | % Germany | | Spain | | % Other | |
| Yes | 42 | 75,00% | 22 | 81,48% | 183 | 85,51% | 31 | 86,11% |
| No | 7 | 12,50% | 1 | 3,70% | 17 | 7,94% | 5 | 13,89% |
| Unsure | 7 | 12,50% | 3 | 11,11% | 12 | 5,61% | 0 | 0,00% |
| Other | 0 | 0,00% | 1 | 3,70% | 2 | 0,93% | 0 | 0,00% |
| TOTAL | 56 | 100,00% | 27 | 100,00% | 214 | 100,00% | 36 | 100,00% |

Table 21 – Willingness to use devices per country

| 2.2 Use digital devices if information health team improved | | | | | | | | |
|---|------------|----------------|------------|----------------|-----------|----------------|----------|----------------|
| | Under 65 | | 65-75 | | 76-85 | | Over 85 | |
| Yes | 145 | 89,51% | 87 | 80,56% | 44 | 77,19% | 2 | 40,00% |
| No | 10 | 6,17% | 10 | 9,26% | 8 | 14,04% | 2 | 40,00% |
| Unsure | 6 | 3,70% | 10 | 9,26% | 5 | 8,77% | 1 | 20,00% |
| Other | 1 | 0,62% | 1 | 0,93% | 0 | 0,00% | 0 | 0,00% |
| TOTAL | 162 | 100,00% | 108 | 100,00% | 57 | 100,00% | 5 | 100,00% |

Table 22 – Willingness to use devices per age

| 2.2 Use digital devices if information health team improved | | | | |
|---|------------|----------------|------------|----------------|
| | Female | | Male | |
| | | % | | % |
| Yes | 89 | 80,91% | 187 | 84,62% |
| No | 11 | 10,00% | 19 | 8,60% |
| Unsure | 9 | 8,18% | 13 | 5,88% |
| Other | 1 | 0,91% | 2 | 0,90% |
| TOTAL | 110 | 100,00% | 221 | 100,00% |

Table 23 – Willingness to use devices per gender

| 2.2 Use digital devices if information health team improved | | | | | | | | | | | | |
|---|---------------------|----------------|-----------|------------------|-----------|-----------------------|------------|----------------|------------|----------------|-----------|----------------|
| | No formal education | Primary school | | Secondary school | | Post-secondary school | | Master degree | | PhD's degree | | % |
| | | % | | % | | % | | % | | % | | % |
| Yes | 6 | 60,00% | 16 | 84,21% | 42 | 80,77% | 89 | 81,65% | 93 | 90,29% | 32 | 80,00% |
| No | 3 | 30,00% | 1 | 5,26% | 5 | 9,62% | 11 | 10,09% | 6 | 5,83% | 4 | 10,00% |
| Unsure | 1 | 10,00% | 2 | 10,53% | 4 | 7,69% | 8 | 7,34% | 4 | 3,88% | 3 | 7,50% |
| Other | 0 | 0,00% | 0 | 0,00% | 1 | 1,92% | 1 | 0,92% | 0 | 0,00% | 1 | 2,50% |
| TOTAL | 10 | 100,00% | 19 | 100,00% | 52 | 100,00% | 109 | 100,00% | 103 | 100,00% | 40 | 100,00% |

Table 24 – Willingness to use devices per academic education

| EDUCATION | | | | |
|-----------------------|------------------|-----------------------|---------------------|---------|
| GENDER | Q2 | Frecuencia | Porcentaje | |
| Female | Yes | PhD's degree | 1 50,0 | |
| | | Secondary school | 1 50,0 | |
| | | Total | 2 100,0 | |
| | I am unsure | Post-secondary school | 1 100,0 | |
| | | Master degree | 3 33,3 | |
| | | PhD's degree | 2 22,2 | |
| | | Post-secondary school | 2 22,2 | |
| | | Primary school | 1 11,1 | |
| | | Secondary school | 1 11,1 | |
| | | Total | 9 100,0 | |
| No | Master degree | 2 18,2 | | |
| | | No formal education | 1 9,1 | |
| | PhD's degree | 1 9,1 | | |
| | | Post-secondary school | 3 27,3 | |
| | Primary school | 1 9,1 | | |
| | | Secondary school | 3 27,3 | |
| | Total | 11 100,0 | | |
| | Yes | Master degree | 30 33,7 | |
| | | | No formal education | 2 2,2 |
| | | PhD's degree | 9 10,1 | |
| Post-secondary school | | | 26 29,2 | |
| Primary school | | 6 6,7 | | |
| | | Secondary school | 16 18,0 | |
| Total | | 89 100,0 | | |
| Male | | PhD's degree | 1 50,0 | |
| | | | Secondary school | 1 50,0 |
| | | | Total | 2 100,0 |
| | I am unsure | Master degree | 1 7,7 | |
| | | No formal education | 1 7,7 | |
| | | PhD's degree | 1 7,7 | |
| | | Post-secondary school | 6 46,2 | |
| | | Primary school | 1 7,7 | |
| | | Secondary school | 3 23,1 | |
| | | Total | 13 100,0 | |
| No | Master degree | 4 21,1 | | |
| | | No formal education | 2 10,5 | |
| | PhD's degree | 3 15,8 | | |
| | | Post-secondary school | 8 42,1 | |
| | Secondary school | 2 10,5 | | |
| | Total | 19 100,0 | | |
| | Yes | Master degree | 63 33,7 | |
| No formal education | | | 4 2,1 | |
| PhD's degree | | 22 11,8 | | |
| | | Post-secondary school | 63 33,7 | |
| Primary school | | 10 5,3 | | |
| Secondary school | | 25 13,4 | | |
| Total | | 187 100,0 | | |

Table 25 – Willingness to use devices per gender and education

During the interviews several participants shared with us the following:

- That they would be willing to use digital devices if doctors/ neurologists could improve patient's care by having data on their health which meant more and more objective information (e.g., medication control, symptomatology monitoring).
- They also said that they would make anything to better communication/networking with the healthcare team (neurologists / kinesiologists / psychologists / ...). Some patients believed that external factors, as time and money, influenced the way in which they were cared for and that valid digital tools might help in this sense.
- They also considered important to have a constant team for the follow-up "to anticipate weak moments".
- Some patients gave us examples of some health data systems where they were already registered to store and share documents and health data (e.g.,

<https://www.monespacesante.fr/>). Others were involved in patient networks (e.g., “Parkipotes”, in France).

The constraints they referred to the use of devices were:

- Those devices that could be intrusive.
- Devices for other purposes, non-medical.
- Procedures that would require too many skills or too much time.

Other participants simply did not like computers/social networks considering those could control their lives and regretting to see human dimension replaced by technology or not really comfortable using them.

Q3 - Concerns about use of technological devices

When we asked participants about their concerns **when using technological devices**, the majority, **63.06%**, told us that in general they were **not worried** about their use.

At least in initial pilot studies privacy concerns and receptivity to telemedicine technologies do not appear to differ across cultural groups and this is what we have also encountered in our study.¹⁵

In terms of some factors that might be of greater concern, participants indicated in first place the time it might take to use them (11.11%), followed by the difficulties they could encounter (9.01%) and also the reluctance to share their health data with other people (5.71%).

2.3 Would any of the following factors concern you if using them? (you can select more than one option, if you like)

| | Answers | Ratio |
|---|---------|---------|
| Too time-consuming | 37 | 11.11 % |
| Not able to handle the device, even with support | 30 | 9.01 % |
| Not willing to share your health data with anyone | 19 | 5.71 % |
| Not concerned about any of these factors | 210 | 63.06 % |
| Other | 28 | 8.41 % |
| No Answer | 22 | 6.61 % |

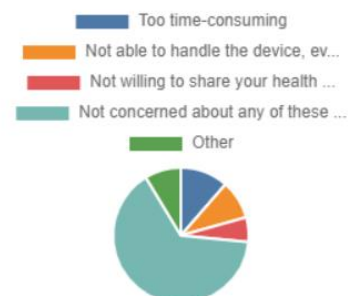


Figure 10

- *Spanish* participants reported the fewest concerns when using technology (71.03%) followed by people from *other Spanish speaking countries* (66.67%). When having concerns those were related by far to their ability to handle the devices (19.44%).

A high number of *German* and *French* participants reported that they were not concerned about those factors when using technology (44.44% and 32.14% respectively). Germans seemed to be most concerned about time consumption (29.63%), scoring low on concerns

¹⁵ Dang et al., 2008; Demiris et al., 2009

about how to use devices (3.70%). French participants were also concerned with the time it could take to use them (28.57%) and secondly, not knowing how to use them (12.50%).

- Regarding age: Participants *under 65* were those who had least concerns about the use of technology (69.14%). Then, people between *65-75* were the most concerned about time consumption (24.07%) and from *76-85* concerns about not being able to handle devices increased (29.82%). The group of people *over 85* is the one with the greatest concerns in the use of technology and these concerns are primarily focused on the ability to use the devices (60%).
- Per gender: We found slightly fewer men than women to be concerned about the use of technology (63.35% and 60.91% respectively). The most important concern for *females* was not being able to handle devices (12.73%) and for *males* the time consuming (11.76%).
- Regarding studies: Those with *non-formal studies* were the most concerned in general. Mostly about time consumption (20%). *Primary school* participants were the most concerned about not being able to handle devices (26.32%). As studies increase with *Post-secondary school*, concerns about the use of technology decreased being the group with *Master's degree* the one with the least concerns related to technology use (66.02%).

| 2.3 Concerns if using technology | France | % | Germany | % | Spain | % | Other | % |
|--|-----------|----------------|-----------|----------------|------------|----------------|-----------|----------------|
| Too time-consuming | 16 | 28,57% | 8 | 29,63% | 15 | 7,01% | 0 | 0,00% |
| Not able to handle devices | 7 | 12,50% | 1 | 3,70% | 14 | 6,54% | 7 | 19,44% |
| Not willing to share data | 2 | 3,57% | 1 | 3,70% | 15 | 7,01% | 0 | 0,00% |
| Not concerned about any of these factors | 18 | 32,14% | 12 | 44,44% | 152 | 71,03% | 24 | 66,67% |
| Other | 8 | 14,29% | 2 | 7,41% | 13 | 6,07% | 2 | 5,56% |
| No answer | 5 | 8,93% | 3 | 11,11% | 5 | 2,34% | 3 | 8,33% |
| TOTAL | 56 | 100,00% | 27 | 100,00% | 214 | 100,00% | 36 | 100,00% |

Table 26 – Concerns about technology use per country

| 2.3 Concerns if using technology | Under 65 | % | 65-75 | % | 76-85 | % | Over 85 | % |
|--|------------|----------------|------------|----------------|-----------|----------------|----------|----------------|
| Too time-consuming | 21 | 12,96% | 26 | 24,07% | 6 | 10,53% | 1 | 20,00% |
| Not able to handle devices | 6 | 3,70% | 19 | 17,59% | 17 | 29,82% | 3 | 60,00% |
| Not willing to share data | 11 | 6,79% | 16 | 14,81% | 8 | 14,04% | 0 | 0,00% |
| Not concerned about any of these factors | 112 | 69,14% | 30 | 27,78% | 18 | 31,58% | 1 | 20,00% |
| Other | 12 | 7,41% | 13 | 12,04% | 3 | 5,26% | 0 | 0,00% |
| No answer | 0 | 0,00% | 4 | 3,70% | 5 | 8,77% | 0 | 0,00% |
| TOTAL | 162 | 100,00% | 108 | 100,00% | 57 | 100,00% | 5 | 100,00% |

Table 27 – Concerns about technology use per age

| 2.3 Concerns if using technology | Female | % | Male | % |
|--|------------|----------------|------------|----------------|
| Too time-consuming | 13 | 11,82% | 26 | 11,76% |
| Not able to handle devices | 14 | 12,73% | 17 | 7,69% |
| Not willing to share data | 6 | 5,45% | 14 | 6,33% |
| Not concerned about any of these factors | 67 | 60,91% | 140 | 63,35% |
| Other | 6 | 5,45% | 21 | 9,50% |
| No answer | 4 | 3,64% | 3 | 1,36% |
| TOTAL | 110 | 100,00% | 221 | 100,00% |

Table 28 – Concerns about technology use per gender

| 2.3 Concerns if using technology | No formal education | | Primary school | | Secondary school | | Post-secondary school | | Master degree | | PhD's degree | |
|--|---------------------|----------------|----------------|----------------|------------------|----------------|-----------------------|----------------|---------------|----------------|--------------|----------------|
| | | % | | % | | % | | % | | % | | % |
| Too time-consuming | 2 | 20,00% | 1 | 5,26% | 5 | 9,62% | 12 | 11,01% | 19 | 18,45% | 3 | 7,50% |
| Not able to handle devices | 2 | 20,00% | 5 | 26,32% | 7 | 13,46% | 14 | 12,84% | 2 | 1,94% | 2 | 5,00% |
| Not willing to share data | 1 | 10,00% | 1 | 5,26% | 4 | 7,69% | 8 | 7,34% | 8 | 7,77% | 3 | 7,50% |
| Not concerned about any of these factors | 3 | 30,00% | 9 | 47,37% | 32 | 61,54% | 69 | 63,30% | 68 | 66,02% | 26 | 65,00% |
| Other | 1 | 10,00% | 1 | 5,26% | 3 | 5,77% | 6 | 5,50% | 6 | 5,83% | 6 | 15,00% |
| No answer | 1 | 10,00% | 2 | 10,53% | 1 | 1,92% | 0 | 0,00% | 0 | 0,00% | 0 | 0,00% |
| TOTAL | 10 | 100,00% | 19 | 100,00% | 52 | 100,00% | 109 | 100,00% | 103 | 100,00% | 40 | 100,00% |

Table 29 – Concerns about technology use per academic education

During interviews participants told us that:

- In general, they found the use of technology not difficult and interesting. Many of them were curious and not worried about any factor, on the contrary, they saw this use as comfortable and very useful.
- Others considered that they knew the basics about computers and felt unsure about their ability. They did not consider the use of devices a waste of time but they thought that technology should be as simple as possible, "so that it doesn't complicate our lives". "To be easy and quick to understand/use, more as the disease progresses".
- Also, that fewer concerns would arise if it could be used in a safe and trusted environment.

Those who showed they had concerns pointed out:

- There should be a usage optimization and improvement of ergonomics to adapt to users' difficulties (specially to face ON/OFF phenomenon).
- They showed some worries about invading their privacy or having to wear a device all day. But these concerns were lessened when it came to data for monitoring their health status.
- Some of them said to be "*from the old era*" and to be tired of tablets, mobiles, watches...and having to do everything through technology. They were looking forward to interact physically more with people.
- Other concerns were related to having difficulties with or misuse technology and they would like to have assistance and instructions (through app or chats) to be helped. In those cases, a team available/reachable for explanations would be needed.
- Some showed concerns about misinterpretations of the data: "*That it actually measures what they want to measure*". Also, about technical problems to expect with these devices.

Q4 - Preference on devices

In terms of devices, the **smartphone was the one chosen by the vast majority (74.34%)**. According to what was said during the interviews, this was due to their familiarity with it as almost all of them had one that used to a greater/lesser extent.

In a second place the shoe sensor (48.3%). As we detected during the interviews, this was due to the fact that it is a passive element with which they consider they do not have to interact with.

With a much lower degree of acceptance, we found computer microphones and webcam (27.92%) and headset microphones (18.25%) with which they seem to be less familiar.

2.4 Which of the following devices would you like to use better? (you can select more than one option, if you like; also none of them)






| | | Answers | Ratio |
|--------------------------------|---|---------|---------|
| Headset microphone |  | 51 | 19.25 % |
| Computer microphone and webcam |  | 74 | 27.92 % |
| Smartphone |  | 197 | 74.34 % |
| Shoe-sensor |  | 128 | 48.3 % |
| No Answer |  | 13 | 4.91 % |

Figure 11

- *French* participants were those who preferred smartphones the most (57.14%). A high number of *Spanish* participants preferred also smartphones (50.47%) together with the shoe sensor (32.71%). *German* people preferred smartphones (44.44%) and were those with the highest preference for computer microphone and webcam and headset microphone, 22.22% (together with participants from *other Spanish-speaking countries*).
- Regarding age groups, people *Under 65* was the one with the highest smartphone preference among participants (51.25%) and those between *65-75* were the ones who preferred shoe sensors the most (28.70%).
- Regarding gender: *Male* participants preferred smartphones (46.15%) and shoe sensors (28.96%) to a greater extent than women.
- If we look at the participants' studies, the group with *Secondary school education* was the one with the strongest preference for smartphones (55.77%). People with *Post-secondary school* had the strongest preference for shoe-sensor (33.03%) and with *PhD's degree* for computers and webcams (32.50%).

| 2.4 Devices preferred | France | % | Germany | % | Spain | % | Other | % |
|--------------------------------|-----------|----------------|-----------|----------------|------------|----------------|-----------|----------------|
| Headset microphone | 2 | 3,57% | 3 | 11,11% | 13 | 6,07% | 4 | 11,11% |
| Computer microphone and webcam | 8 | 14,29% | 6 | 22,22% | 18 | 8,41% | 8 | 22,22% |
| Smartphone | 32 | 57,14% | 12 | 44,44% | 108 | 50,47% | 13 | 36,11% |
| Shoe-sensor | 12 | 21,43% | 5 | 18,52% | 70 | 32,71% | 10 | 27,78% |
| No answer | 2 | 3,57% | 1 | 3,70% | 5 | 2,34% | 1 | 2,78% |
| TOTAL | 56 | 100,00% | 27 | 100,00% | 214 | 100,00% | 36 | 100,00% |

Table 30 – Preference on devices per country

| 2.4 Devices preferred | Under 65 | % | 65-75 | % | 76-85 | % | Over 85 | % |
|--------------------------------|------------|----------------|------------|----------------|-----------|----------------|----------|----------------|
| Headset microphone | 16 | 10,00% | 4 | 3,70% | 4 | 7,02% | 1 | 20,00% |
| Computer microphone and webcam | 19 | 11,88% | 16 | 14,81% | 9 | 15,79% | 1 | 20,00% |
| Smartphone | 82 | 51,25% | 55 | 50,93% | 25 | 43,86% | 2 | 40,00% |
| Shoe-sensor | 41 | 25,63% | 31 | 28,70% | 14 | 24,56% | 1 | 20,00% |
| No answer | 2 | 1,25% | 2 | 1,85% | 5 | 8,77% | 0 | 0,00% |
| TOTAL | 160 | 100,00% | 108 | 100,00% | 57 | 100,00% | 5 | 100,00% |

Table 31 – Preference on devices per age

| 2.4 Devices preferred | Female | % | Male | % |
|--------------------------------|------------|----------------|------------|----------------|
| Headset microphone | 12 | 10,91% | 21 | 9,50% |
| Computer microphone and webcam | 21 | 19,09% | 30 | 13,57% |
| Smartphone | 47 | 42,73% | 102 | 46,15% |
| Shoe-sensor | 25 | 22,73% | 64 | 28,96% |
| No answer | 5 | 4,55% | 4 | 1,81% |
| TOTAL | 110 | 100,00% | 221 | 100,00% |

Table 32 – Preference on devices per gender

| 2.4 Devices preferred | No formal education | % | Primary school | % | Secondary school | % | Post-secondary school | % | Master degree | % | PhD's degree | % |
|--------------------------------|---------------------|----------------|----------------|----------------|------------------|----------------|-----------------------|----------------|---------------|----------------|--------------|----------------|
| Headset microphone | 2 | 20,00% | 4 | 21,05% | 7 | 13,46% | 9 | 8,26% | 5 | 4,85% | 4 | 10,00% |
| Computer microphone and webcam | 1 | 10,00% | 2 | 10,53% | 8 | 15,38% | 11 | 10,09% | 14 | 13,59% | 13 | 32,50% |
| Smartphone | 4 | 40,00% | 8 | 42,11% | 29 | 55,77% | 52 | 47,71% | 57 | 55,34% | 17 | 42,50% |
| Shoe-sensor | 3 | 30,00% | 5 | 26,32% | 8 | 15,38% | 36 | 33,03% | 26 | 25,24% | 5 | 12,50% |
| No answer | 0 | 0,00% | 0 | 0,00% | 0 | 0,00% | 1 | 0,92% | 1 | 0,97% | 1 | 2,50% |
| TOTAL | 10 | 100,00% | 19 | 100,00% | 52 | 100,00% | 109 | 100,00% | 103 | 100,00% | 40 | 100,00% |

Table 33 – Preference on devices per academic education

During the interviews several participants told us:

- They liked to use smartwatches because they could see their health data (like an ECG), activity data, sleep and because it generated reports and they thought could be consulted with their doctor/any other health specialist.
- Some would prefer the latest models/devices as they would be more accurate and improved over the previous ones but in general, they preferred their own ones and those that were easy to use/familiar and did not want technology to be too intrusive.
- Some participants stressed that they did not feel comfortable touching small screens as those were not suitable for Parkinson's patients, preferring to use a tablet or a computer with the mouse keyboard. Smartphones were not comfortable for others as they were not able to grab it anymore. Voice command were not always optimized either.

On the other hand, they also commented the following:

- That there was a digital space called "*My health space*", for beneficiaries of French health insurance plan, where data was freely shared with a catalogue of services and Apps for taking medical appointments, measuring blood pressure, having medicines delivered at home.
- The use of a shared computer file to monitor progress (*Parkinson's digital ID card*) in order to decompartmentalize information.

Q5 - Preferences on place and frequency of use

As for the way they are used, **almost half of the participants (48.95%) indicated that they did not mind as long as it was the way indicated by the professionals** as the most optimal.

In any case, it seemed that in general they preferred to use it at home (46.25%) rather than during regular hospital visits (17.42%).

2.5 If you were to use them, how would you prefer to do it?

| | Answers | Ratio |
|--|---------|---------|
| At home, on a regular basis (i.e. daily) | 96 | 28.83 % |
| At home, when necessary (i.e. monthly) | 58 | 17.42 % |
| At periodical hospital visits | 11 | 3.3 % |
| Either option if needed | 163 | 48.95 % |
| None of them | 3 | 0.9 % |
| No Answer | 2 | 0.6 % |

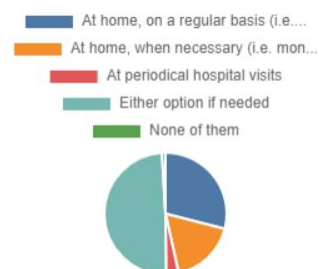


Figure 12

- *German* participants were those more willing to adapt to the place and time considered by the professional (59.26%) mostly males with master's degree or secondary school. People from *Spain* and *other Spanish speaking countries* preferred the use at home on a regular basis (55.61% and 55.56% respectively) as French participants (42.86%).
- Depending on age, people *under 65* were the most adapted to the decision of the professional in the use of devices (53.09%) and were least likely to prefer to use them at periodical hospital visits (0.62%). People between *65-75* also had a high level of adaptability according to the guidelines of the professionals (46.30%). This was the age group that most preferred the use of devices at home on a regular basis (31.48%).
- *Females* showed greater adaptability to the option of use that was needed (50.91%). Slightly more females than males preferred the option of at home on a regular basis (29.09%).
- Per academic education: Those with *master's degree* were the most likely to indicate that they would make use of devices depending on what would need to be done (57.28%).

| 2.5 Type of use preferred | France | % | Germany | % | Spain | % | Other | % |
|--|-----------|----------------|-----------|----------------|------------|----------------|-----------|----------------|
| At home, on a regular basis (i.e. daily) | 24 | 42,86% | 3 | 11,11% | 49 | 22,90% | 20 | 55,56% |
| At home, when necessary (i.e. monthly) | 12 | 21,43% | 6 | 22,22% | 39 | 18,22% | 1 | 2,78% |
| At periodical hospital visits | 5 | 8,93% | 1 | 3,70% | 4 | 1,87% | 1 | 2,78% |
| Either option if needed | 15 | 26,79% | 16 | 59,26% | 119 | 55,61% | 13 | 36,11% |
| None of them | 0 | 0,00% | 0 | 0,00% | 2 | 0,93% | 1 | 2,78% |
| No answer | 0 | 0,00% | 1 | 3,70% | 1 | 0,47% | 0 | 0,00% |
| TOTAL | 56 | 100,00% | 27 | 100,00% | 214 | 100,00% | 36 | 100,00% |

Table 34 – Preference of use per country

| 2.5 Type of use preferred | Under 65 | % | 65-75 | % | 76-85 | % | Over 85 | % |
|--|------------|----------------|------------|----------------|-----------|----------------|----------|----------------|
| At home, on a regular basis (i.e. daily) | 45 | 27,78% | 34 | 31,48% | 15 | 26,32% | 1 | 20,00% |
| At home, when necessary (i.e. monthly) | 26 | 16,05% | 17 | 15,74% | 14 | 24,56% | 1 | 20,00% |
| At periodical hospital visits | 1 | 0,62% | 6 | 5,56% | 3 | 5,26% | 1 | 20,00% |
| Either option if needed | 86 | 53,09% | 50 | 46,30% | 25 | 43,86% | 2 | 40,00% |
| None of them | 2 | 1,23% | 1 | 0,93% | 0 | 0,00% | 0 | 0,00% |
| No answer | 2 | 1,23% | 0 | 0,00% | 0 | 0,00% | 0 | 0,00% |
| TOTAL | 162 | 100,00% | 108 | 100,00% | 57 | 100,00% | 5 | 100,00% |

Table 35 – Preference of use per age

| 2.5 Type of use preferred | Female | % | Male | % |
|--|------------|----------------|------------|----------------|
| At home, on a regular basis (i.e. daily) | 32 | 29,09% | 63 | 28,51% |
| At home, when necessary (i.e. monthly) | 18 | 16,36% | 40 | 18,10% |
| At periodical hospital visits | 3 | 2,73% | 8 | 3,62% |
| Either option if needed | 56 | 50,91% | 106 | 47,96% |
| None of them | 1 | 0,91% | 2 | 0,90% |
| No answer | 0 | 0,00% | 2 | 0,90% |
| TOTAL | 110 | 100,00% | 221 | 100,00% |

Table 36 – Preference of use per gender

| 2.5 Type of use preferred | No formal education | % | Primary school | % | Secondary school | % | Post-secondary school | % | Master degree | % | PhD's degree | % |
|--|---------------------|----------------|----------------|----------------|------------------|----------------|-----------------------|----------------|---------------|----------------|--------------|----------------|
| At home, on a regular basis (i.e. daily) | 2 | 20,00% | 6 | 31,58% | 16 | 30,77% | 34 | 31,19% | 24 | 23,30% | 14 | 35,00% |
| At home, when necessary (i.e. monthly) | 3 | 30,00% | 3 | 15,79% | 7 | 13,46% | 17 | 15,60% | 18 | 17,48% | 10 | 25,00% |
| At periodical hospital visits | 0 | 0,00% | 0 | 0,00% | 2 | 3,85% | 5 | 4,59% | 1 | 0,97% | 3 | 7,50% |
| Either option if needed | 5 | 50,00% | 10 | 52,63% | 26 | 50,00% | 50 | 45,87% | 59 | 57,28% | 13 | 32,50% |
| None of them | 0 | 0,00% | 0 | 0,00% | 0 | 0,00% | 3 | 2,75% | 0 | 0,00% | 0 | 0,00% |
| No answer | 0 | 0,00% | 0 | 0,00% | 1 | 1,92% | 0 | 0,00% | 1 | 0,97% | 0 | 0,00% |
| TOTAL | 10 | 100,00% | 19 | 100,00% | 52 | 100,00% | 109 | 100,00% | 103 | 100,00% | 40 | 100,00% |

Table 37 – Preference of use per academic education

| COUNTRY | Q5 | Frecuencia | Porcentaje | |
|--------------|--|-------------------------------|------------|---------|
| France | At home, on a regular basis (i.e. daily) | Female | 8 33,3 | |
| | | Male | 16 66,7 | |
| | | Total | 24 100,0 | |
| | At home, when necessary (i.e. monthly) | Female | 4 33,3 | |
| | | Male | 8 66,7 | |
| | | Total | 12 100,0 | |
| | At periodical hospital visits | Female | 1 20,0 | |
| | | Male | 4 80,0 | |
| | | Total | 5 100,0 | |
| | Either option if needed | Female | 8 53,3 | |
| | | Male | 7 46,7 | |
| | | Total | 15 100,0 | |
| Germany | At home, on a regular basis (i.e. daily) | Male | 1 100,0 | |
| | | Female | 2 66,7 | |
| | | Male | 1 33,3 | |
| | At home, when necessary (i.e. monthly) | Total | 3 100,0 | |
| | | Female | 1 16,7 | |
| | | Male | 5 83,3 | |
| | At periodical hospital visits | Total | 6 100,0 | |
| | | Female | 1 100,0 | |
| | | Male | 1 100,0 | |
| | Either option if needed | Female | 3 18,8 | |
| | | Male | 13 81,3 | |
| | | Total | 16 100,0 | |
| Spain | At home, on a regular basis (i.e. daily) | Female | 6 30,0 | |
| | | Male | 14 70,0 | |
| | | Total | 20 100,0 | |
| | At home, when necessary (i.e. monthly) | Male | 1 100,0 | |
| | | At periodical hospital visits | Male | 1 100,0 |
| | | Female | 5 38,5 | |
| | Either option if needed | Male | 8 61,5 | |
| | | Total | 13 100,0 | |
| | | Female | 1 100,0 | |
| | None of them | Male | 1 100,0 | |
| | | Female | 1 100,0 | |
| | | Male | 1 100,0 | |
| Other | At home, on a regular basis (i.e. daily) | Female | 1 2,0 | |
| | | Male | 16 32,7 | |
| | | Total | 32 65,3 | |
| | At home, when necessary (i.e. monthly) | Female | 49 100,0 | |
| | | Male | 13 33,3 | |
| | | Total | 26 66,7 | |
| | At periodical hospital visits | Female | 39 100,0 | |
| | | Male | 2 50,0 | |
| | | Total | 2 50,0 | |
| | Either option if needed | Female | 4 100,0 | |
| | | Male | 1 8 | |
| | | Total | 1 8 | |
| None of them | Female | 40 33,6 | | |
| | Male | 78 65,5 | | |
| | Total | 119 100,0 | | |
| None of them | Male | 2 100,0 | | |
| | Female | 2 100,0 | | |
| | Total | 4 100,0 | | |

Table 38 – Preference of use per country and gender

| Germany | Master degree | 1 | 100,0 |
|--|-----------------------|----|-------|
| At home, on a regular basis (i.e. daily) | Master degree | 2 | 66,7 |
| | Secondary school | 1 | 33,3 |
| | Total | 3 | 100,0 |
| At home, when necessary (i.e. monthly) | Master degree | 1 | 16,7 |
| | No formal education | 1 | 16,7 |
| | PhD's degree | 1 | 16,7 |
| | Post-secondary school | 1 | 16,7 |
| | Secondary school | 2 | 33,3 |
| | Total | 6 | 100,0 |
| At periodical hospital visits | Secondary school | 1 | 100,0 |
| Either option if needed | Master degree | 6 | 37,5 |
| | No formal education | 1 | 6,3 |
| | PhD's degree | 1 | 6,3 |
| | Post-secondary school | 2 | 12,5 |
| | Secondary school | 6 | 37,5 |
| | Total | 16 | 100,0 |

Table 39 – Preference of use in German participants per academic education

During the interviews, participants told us:

- If the protocol to follow with devices would be easy (like with the use of a smartwatch), they preferred to use them at home on a regular basis (“*I don't find it difficult and the advantage is that I don't have to go anywhere to use any of the devices you mentioned*”) with a support team behind to supervise the process in case they might need any kind of assistance.
- They thought that the most logical and practical way to collect data and parameters was on a regular basis, because sporadically: “*it is not going to be as real*”. “*I wouldn't mind using it all day, I don't see any disadvantages and this information is more real, more objective*”.
- They were also inclined to adapt the duration of its use depending on the device, its functionality and its data collection requirements.
- Regarding collection data at hospital, they thought this to be more hectic, less comfortable, with a loss of time with lots of people around and the difficulties of transport.

Q6 - Preference on duration of data collection sessions

As in the previous question, for the preferred duration of a data collection session, **37.54% of participants indicated that they would do whatever the doctor/expert would indicate**. However, a convenient duration of an active session for them seems would **be between 15-30 minutes (21.02%)**.

2.6 What would be a convenient duration of a data collection session for you?

| | Answers | Ratio |
|---------------------------------|---------|---------|
| >15 minutes | 57 | 17.12 % |
| 15-30 minutes | 70 | 21.02 % |
| 30 minutes-1 hour | 17 | 5.11 % |
| I do not mind | 62 | 18.62 % |
| Whatever the doctor-expert says | 125 | 37.54 % |
| No Answer | 2 | 0.6 % |

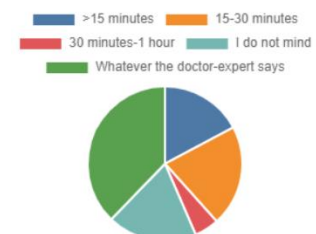


Figure 13

- Participants from *Spain* were most likely to indicate that they would adapt the duration of their sessions to what the expert would say (42.52%) mostly if they were men with post-secondary school studies. Participants from *France* and *Germany* showed preference for a 15-30 minutes session (33.93% and 33.33% respectively).
- Regarding age: People *Under 65* were the ones to indicate more that a convenient duration for them would be the indicated by the expert (40.74%). Those *Over 85* said that they preferred sessions of less than 15 minutes (40%).
- Results were very similar between *females* and *males* and also regarding different levels of education. Those with Master's *degree* were more likely to prefer shorter sessions lasting less than 15 minutes (20.39%).

| 2.6 Convenient duration of use | France | % | Germany | % | Spain | % | Other | % |
|--------------------------------|-----------|----------------|-----------|----------------|------------|----------------|-----------|----------------|
| >15 minutes | 12 | 21,43% | 6 | 22,22% | 35 | 16,36% | 4 | 11,11% |
| 15-30 minutes | 19 | 33,93% | 9 | 33,33% | 38 | 17,76% | 4 | 11,11% |
| 30 minutes -1 hour | 6 | 10,71% | 0 | 0,00% | 6 | 2,80% | 5 | 13,89% |
| I do not mind | 5 | 8,93% | 6 | 22,22% | 44 | 20,56% | 7 | 19,44% |
| Whatever the doctor/expert say | 13 | 23,21% | 6 | 22,22% | 91 | 42,52% | 15 | 41,67% |
| No answer | 1 | 1,79% | 0 | 0,00% | 0 | 0,00% | 1 | 2,78% |
| TOTAL | 56 | 100,00% | 27 | 100,00% | 214 | 100,00% | 36 | 100,00% |

Table 40 – Preference on duration data session per country

| 2.6 Convenient duration of use | Under 65 | % | 65-75 | % | 76-85 | % | Over 85 | % |
|--------------------------------|------------|----------------|------------|----------------|-----------|----------------|----------|----------------|
| >15 minutes | 25 | 15,43% | 18 | 16,67% | 12 | 21,05% | 2 | 40,00% |
| 15-30 minutes | 25 | 15,43% | 28 | 25,93% | 17 | 29,82% | 0 | 0,00% |
| 30 minutes -1 hour | 8 | 4,94% | 7 | 6,48% | 2 | 3,51% | 0 | 0,00% |
| I do not mind | 37 | 22,84% | 19 | 17,59% | 5 | 8,77% | 0 | 0,00% |
| Whatever the doctor/expert say | 66 | 40,74% | 35 | 32,41% | 21 | 36,84% | 3 | 60,00% |
| No answer | 1 | 0,62% | 1 | 0,93% | 0 | 0,00% | 0 | 0,00% |
| TOTAL | 162 | 100,00% | 108 | 100,00% | 57 | 100,00% | 5 | 100,00% |

Table 41 – Preference on duration data session per age

| 2.6 Convenient duration of use | Female | % | Male | % |
|---------------------------------|------------|----------------|------------|----------------|
| >15 minutes | 19 | 17,27% | 38 | 17,19% |
| 15-30 minutes | 24 | 21,82% | 46 | 20,81% |
| 30 minutes -1 hour | 6 | 5,45% | 10 | 4,52% |
| I do not mind | 21 | 19,09% | 40 | 18,10% |
| Whatever the doctor/expert says | 40 | 36,36% | 85 | 38,46% |
| No answer | 0 | 0,00% | 2 | 0,90% |
| TOTAL | 110 | 100,00% | 221 | 100,00% |

Table 42 – Preference on duration data session per gender

| 2.6 Convenient duration of use | No formal education | % | Primary school | % | Secondary school | % | Post-secondary school | % | Master degree | % | PhD's degree | % |
|---------------------------------|---------------------|----------------|----------------|----------------|------------------|----------------|-----------------------|----------------|---------------|----------------|--------------|----------------|
| >15 minutes | 0 | 0,00% | 2 | 10,53% | 10 | 19,23% | 17 | 15,60% | 21 | 20,39% | 7 | 17,50% |
| 15-30 minutes | 3 | 30,00% | 3 | 15,79% | 8 | 15,38% | 28 | 25,69% | 16 | 15,53% | 12 | 30,00% |
| 30 minutes -1 hour | 2 | 20,00% | 0 | 0,00% | 2 | 3,85% | 3 | 2,75% | 6 | 5,83% | 4 | 10,00% |
| I do not mind | 1 | 10,00% | 2 | 10,53% | 9 | 17,31% | 24 | 22,02% | 19 | 18,45% | 7 | 17,50% |
| Whatever the doctor/expert says | 4 | 40,00% | 12 | 63,16% | 23 | 44,23% | 35 | 32,11% | 41 | 39,81% | 10 | 25,00% |
| No answer | 0 | 0,00% | 0 | 0,00% | 0 | 0,00% | 2 | 1,83% | 0 | 0,00% | 0 | 0,00% |
| TOTAL | 10 | 100,00% | 19 | 100,00% | 52 | 100,00% | 109 | 100,00% | 103 | 100,00% | 40 | 100,00% |

Table 43 – Preference on duration data session per academic education

| | | GENDER | | |
|---------------------------------|---------------------------------|---------------|------------|----------|
| COUNTRY | Q6 | Frecuencia | Porcentaje | |
| France | >15 minutes | Male | 1 100,0 | |
| | | Female | 3 25,0 | |
| | | Male | 9 75,0 | |
| | 15-30 minutes | Female | 7 36,8 | |
| | | Male | 12 63,2 | |
| | | Total | 19 100,0 | |
| | 30 minutes-1 hour | Female | 3 50,0 | |
| | | Male | 3 50,0 | |
| | | Total | 6 100,0 | |
| | I do not mind | Female | 2 40,0 | |
| | | Male | 3 60,0 | |
| | | Total | 5 100,0 | |
| | Whatever the doctor-expert says | Female | 6 46,2 | |
| | | Male | 7 53,8 | |
| | | Total | 13 100,0 | |
| | Germany | >15 minutes | Female | 2 33,3 |
| | | | Male | 4 66,7 |
| | | | Total | 6 100,0 |
| 15-30 minutes | | Female | 2 22,2 | |
| | | Male | 7 77,8 | |
| | | Total | 9 100,0 | |
| I do not mind | | Female | 1 16,7 | |
| | | Male | 5 83,3 | |
| | | Total | 6 100,0 | |
| Whatever the doctor-expert says | | Female | 1 16,7 | |
| | | Male | 5 83,3 | |
| | | Total | 6 100,0 | |
| Other | | >15 minutes | Male | 1 100,0 |
| | | | Female | 1 25,0 |
| | | | Male | 3 75,0 |
| | | 15-30 minutes | Female | 1 25,0 |
| | | | Male | 3 75,0 |
| | | | Total | 4 100,0 |
| | 30 minutes-1 hour | Female | 1 20,0 | |
| | | Male | 4 80,0 | |
| | | Total | 5 100,0 | |
| | I do not mind | Female | 2 28,6 | |
| | | Male | 5 71,4 | |
| | | Total | 7 100,0 | |
| | Whatever the doctor-expert says | Female | 7 46,7 | |
| | | Male | 8 53,3 | |
| | | Total | 15 100,0 | |
| | Spain | >15 minutes | Female | 13 37,1 |
| | | | Male | 22 62,9 |
| | | | Total | 35 100,0 |
| 15-30 minutes | | Female | 14 36,8 | |
| | | Male | 24 63,2 | |
| | | Total | 38 100,0 | |
| 30 minutes-1 hour | | Female | 1 16,7 | |
| | | Male | 2 33,3 | |
| | | Male | 3 50,0 | |
| I do not mind | | Female | 1 2,3 | |
| | | Female | 16 36,4 | |
| | | Male | 27 61,4 | |
| Whatever the doctor-expert says | | Female | 44 100,0 | |
| | | Male | 26 28,6 | |
| | | Male | 65 71,4 | |
| Total | | Female | 91 100,0 | |
| | | Male | 91 100,0 | |
| | | Total | 182 100,0 | |

Table 44 – Preference on duration data session per country and gender

| | | EDUCATION | |
|---------------------------------|-----------------------|-----------------------|------------|
| COUNTRY | Q6 | Frecuencia | Porcentaje |
| Spain | >15 minutes | Post-secondary school | 4 26,7 |
| | | Secondary school | 3 20,0 |
| | | Total | 15 100,0 |
| | 15-30 minutes | Master degree | 13 37,1 |
| | | PhD's degree | 6 17,1 |
| | | Post-secondary school | 9 25,7 |
| | | Primary school | 2 5,7 |
| | | Secondary school | 5 14,3 |
| | | Total | 35 100,0 |
| | | Master degree | 10 26,3 |
| | No formal education | 1 2,6 | |
| | 30 minutes-1 hour | PhD's degree | 7 18,4 |
| | | Post-secondary school | 12 31,6 |
| | | Primary school | 3 7,9 |
| | | Secondary school | 5 13,2 |
| | | Total | 38 100,0 |
| | | Master degree | 2 33,3 |
| | | No formal education | 2 33,3 |
| I do not mind | PhD's degree | 2 33,3 | |
| | Total | 6 100,0 | |
| | Master degree | 11 25,0 | |
| | PhD's degree | 6 13,6 | |
| | Post-secondary school | 19 43,2 | |
| | Primary school | 2 4,5 | |
| | Secondary school | 6 13,6 | |
| Whatever the doctor-expert says | Total | 44 100,0 | |
| | Master degree | 25 27,5 | |
| | No formal education | 3 3,3 | |
| | PhD's degree | 8 8,8 | |
| | Post-secondary school | 26 28,6 | |
| | Primary school | 12 13,2 | |
| | Secondary school | 17 18,7 | |
| Total | Total | 91 100,0 | |
| | Female | 91 100,0 | |
| | Male | 91 100,0 | |

Table 45 – Preference on duration data session in Spanish participants per academic education

During the interviews, participants indicated us:

- That the convenient duration of a data collection session would be that one the doctor/expert deemed appropriate as they were those who knew and they trusted their opinion/they would do the best for their benefit.

- They were aware that depending on what needed to be measured, sessions should be of different lengths and they were generally willing to adapt to it as long as this was useful.
- They pointed out that it would depend on the condition of the patient (“*considering the non-linear Parkinson’s disease condition*”), the amount of information requested and the context and mode of obtaining it.
- In general, if it was done at home, the restrictions were fewer and the sessions could be longer and even continuous over 1 week-1month. At hospital 30 min to 1 hour each visit, trying to avoid to return to the hospital very often.

Q7 - Preference on feedback

As for the feedback received from the obtention of their data, almost all participants (**94.29%**) **indicated that they would like to receive information about their health**, which clearly showed their preferences in this regard and that they were often not taken into account, especially during research studies.

2.7 If you were using a device for the purpose of extracting data to inform professionals about your health status, would you also like to receive some feedback?

| | Answers | Ratio |
|-------------|---------|---------|
| Yes | 314 | 94.29 % |
| No | 7 | 2.1 % |
| I am unsure | 12 | 3.6 % |
| No Answer | 0 | 0 % |

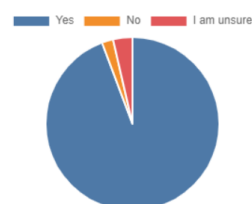


Figure 14

- 100% of participants from other *Spanish speaking countries* wanted to receive feedback about their health data. In the other countries there were no significant differences. Almost all patients wanted to receive feedback.
- *Over 85* was the age group in which we found a higher percentage of people indicating that they would not like to receive feedback (20%).
- Slightly more *females* preferred not to have feedback (4.55%) or were more insecure about it (3.64%) than *males*.
- *Primary* and *Secondary school* participants were those that indicated that they preferred to receive feedback the most (100% and 96.15% respectively).

| 2.7 Like to receive feedback | France | % | Germany | % | Spain | % | Other | % |
|------------------------------|-----------|----------------|-----------|----------------|------------|----------------|-----------|----------------|
| Yes | 54 | 96,43% | 26 | 96,30% | 198 | 92,52% | 36 | 100,00% |
| No | 0 | 0,00% | 0 | 0,00% | 7 | 3,27% | 0 | 0,00% |
| Unsure | 2 | 3,57% | 1 | 3,70% | 9 | 4,21% | 0 | 0,00% |
| No answer | 0 | 0,00% | 0 | 0,00% | 0 | 0,00% | 0 | 0,00% |
| TOTAL | 56 | 100.00% | 27 | 100.00% | 214 | 100.00% | 36 | 100.00% |

Table 46 – Preference on feedback per country

| 2.7 Like to receive feedback | Under 65 | % | 65-75 | % | 76-85 | % | Over 85 | % |
|------------------------------|------------|----------------|------------|----------------|-----------|----------------|----------|----------------|
| Yes | 152 | 93,83% | 104 | 96,30% | 53 | 92,98% | 4 | 80,00% |
| No | 3 | 1,85% | 0 | 0,00% | 3 | 5,26% | 1 | 20,00% |
| Unsure | 7 | 4,32% | 4 | 3,70% | 1 | 1,75% | 0 | 0,00% |
| No answer | 0 | 0,00% | 0 | 0,00% | 0 | 0,00% | 0 | 0,00% |
| TOTAL | 162 | 100,00% | 108 | 100,00% | 57 | 100,00% | 5 | 100,00% |

Table 47 – Preference on feedback per age

| 2.7 Like to receive feedback | Female | % | Male | % |
|------------------------------|------------|----------------|------------|----------------|
| Yes | 101 | 91,82% | 212 | 95,93% |
| No | 5 | 4,55% | 5 | 2,26% |
| Unsure | 4 | 3,64% | 4 | 1,81% |
| No answer | 0 | 0,00% | 0 | 0,00% |
| TOTAL | 110 | 100,00% | 221 | 100,00% |

Table 48 – Preference on duration data session per gender

| 2.7 Like to receive feedback | No formal education | | Primary school | | Secondary school | | Post-secondary school | | Master degree | | PhD's degree | |
|------------------------------|---------------------|----------------|----------------|----------------|------------------|----------------|-----------------------|----------------|---------------|----------------|--------------|----------------|
| | | % | | % | | % | | % | | % | | % |
| Yes | 9 | 90,00% | 19 | 100,00% | 50 | 96,15% | 102 | 93,58% | 97 | 94,17% | 37 | 92,50% |
| No | 0 | 0,00% | 0 | 0,00% | 2 | 3,85% | 1 | 0,92% | 2 | 1,94% | 2 | 5,00% |
| Unsure | 1 | 10,00% | 0 | 0,00% | 0 | 0,00% | 6 | 5,50% | 4 | 3,88% | 1 | 2,50% |
| No answer | 0 | 0,00% | 0 | 0,00% | 0 | 0,00% | 0 | 0,00% | 0 | 0,00% | 0 | 0,00% |
| TOTAL | 10 | 100,00% | 19 | 100,00% | 52 | 100,00% | 109 | 100,00% | 103 | 100,00% | 40 | 100,00% |

Table 49 – Preference on duration data session per academic education

During the interviews, participants indicated us:

- That it was essential to have a regular feedback in terms of data collection (“*To know what have they done with your variables and data*”) and also conclusions (“*To be able to have a report*”) about their health condition. “*It is important to have reports for dissemination to the right professionals. This would improve the information circuit*”.
- In general, what they indicated was that in general “*What happens is that you don't get any information back and that's demotivating*”; “*Yes, it is essential to have a regular feedback It must be an equitable relationship: giving data must imply receiving feedback*”. Some patient deplored a lack of collaborative tools for info sharing (e.g., *Quebec Parkinson*).
- Many interviewees told us that they would like researchers to create news in media that were accessible to them (such as the paper magazine) explaining in a “*more human language*” the objectives of many of these projects.
- A small percentage also thought it was not necessary to receive this feedback because they would not understand/be able to use it.

ACCEPTANCE OF THE USE OF PERSONAL DATA

Q8 - Acceptance of use of personal data for treatment/healthcare

Regarding the acceptance of data obtained through digital devices for treatment/health care purposes, the vast majority, **90.69%**, indicate that they were in favor. Far behind, 6.01% indicated that they were not sure, and only 2.4% seemed to be not in favour.

3.1 Would you accept the use of your physical or mental state data, gathered through digital devices (i.e., smartphone, tablet, computer, specific wearable device –gait sensor on a shoe), for your medical treatment and health care purposes?

| | Answers | Ratio |
|-------------|---------|---------|
| Yes | 302 | 90.69 % |
| No | 8 | 2.4 % |
| I am unsure | 20 | 6.01 % |
| No Answer | 3 | 0.9 % |

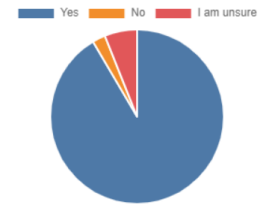


Figure 15

- Participants from *other Spanish speaking countries* were those to agree the most with the idea of using the data obtained through digital devices for medical treatment (97.22%) followed by *German* participants (92.59%). The lowest percentage was France with 85.71% of participants in favour.
- Regarding age: The age group of people *under 65* was the most in favour of using this type of data for medical treatment (95.68%) being the group of *over 85* the one least in favour of using this type of data for medical treatment, 80%. Yet the percentage was still very high.
- Men were slightly more in favour of using data for medical treatment (91.40%) than woman (89.09%) and those with doubts (7.27%) were higher among women.
- All participants with *non-formal education* were in favour of this type of data use (100%). The number of *PhD's degree* participants in favour was high (82.50%). This was also the group with the highest percentage of participants not in favour (5%) and with more doubts (12.50%).

| 3.1 Use of data for medical treatment | France | % | Germany | % | Spain | % | Other | % |
|---------------------------------------|-----------|----------------|-----------|----------------|------------|----------------|-----------|----------------|
| Yes | 48 | 85,71% | 25 | 92,59% | 194 | 90,65% | 35 | 97,22% |
| No | 2 | 3,57% | 0 | 0,00% | 6 | 2,80% | 0 | 0,00% |
| Unsure | 5 | 8,93% | 2 | 7,41% | 12 | 5,61% | 1 | 2,78% |
| No answer | 1 | 1,79% | 0 | 0,00% | 2 | 0,93% | 0 | 0,00% |
| TOTAL | 56 | 100,00% | 27 | 100,00% | 214 | 100,00% | 36 | 100,00% |

Table 50 – Acceptance on data use per country

| 3.1 Use of data for medical treatment | Under 65 | % | 65-75 | % | 76-85 | % | Over 85 | % |
|---------------------------------------|------------|----------------|------------|----------------|-----------|----------------|----------|----------------|
| Yes | 155 | 95,68% | 96 | 88,89% | 46 | 80,70% | 4 | 80,00% |
| No | 3 | 1,85% | 1 | 0,93% | 4 | 7,02% | 0 | 0,00% |
| Unsure | 2 | 1,23% | 11 | 10,19% | 6 | 10,53% | 1 | 20,00% |
| No answer | 2 | 1,23% | 0 | 0,00% | 1 | 1,75% | 0 | 0,00% |
| TOTAL | 162 | 100,00% | 108 | 100,00% | 57 | 100,00% | 5 | 100,00% |

Table 51 – Acceptance on data use per age

| 3.1 Use of data for medical treatment | Female | % | Male | % |
|---------------------------------------|------------|----------------|------------|----------------|
| Yes | 98 | 89,09% | 202 | 91,40% |
| No | 3 | 2,73% | 4 | 1,81% |
| Unsure | 8 | 7,27% | 13 | 5,88% |
| No answer | 1 | 0,91% | 2 | 0,90% |
| TOTAL | 110 | 100,00% | 221 | 100,00% |

Table 52 – Acceptance on data use per gender

| 3.1 Use of data for medical treatment | No formal education | | Primary school | | Secondary school | | Post-secondary school | | Master degree | | PhD's degree | |
|---------------------------------------|---------------------|----------------|----------------|----------------|------------------|----------------|-----------------------|----------------|---------------|----------------|--------------|----------------|
| | | % | | % | | % | | % | | % | | % |
| Yes | 10 | 100,00% | 18 | 94,74% | 45 | 86,54% | 96 | 88,07% | 100 | 97,09% | 33 | 82,50% |
| No | 0 | 0,00% | 0 | 0,00% | 2 | 3,85% | 4 | 3,67% | 0 | 0,00% | 2 | 5,00% |
| Unsure | 0 | 0,00% | 0 | 0,00% | 4 | 7,69% | 8 | 7,34% | 3 | 2,91% | 5 | 12,50% |
| No answer | 0 | 0,00% | 1 | 5,26% | 1 | 1,92% | 1 | 0,92% | 0 | 0,00% | 0 | 0,00% |
| TOTAL | 10 | 100,00% | 19 | 100,00% | 52 | 100,00% | 109 | 100,00% | 103 | 100,00% | 40 | 100,00% |

Table 53 – Acceptance on data use per academic education

During the interviews, participants indicated us:

- In general, what they commented is that they would accept such use if performed by the medical team that was in charge of the patient's follow-up. This was provided that traditional models of communication were not completely switched to virtual as there was no complete reliance on technology yet.
- That anything that would benefit the disease's treatment/intervention was fundamental for the Parkinson's patient right now and also for future people with the disease.
- They said that *"It is important to collect this kind of data in order to be able to improve or research medical treatments, for health purposes"*.
- At some point there were some patients that mentioned *"It is important to collect physical but also mental data to be able to understand more aspects of the disease"*.
- The only requirements they mentioned were that their privacy should be respected as much as possible and that it should be used only for medical purposes.
- Some fear of phone loss/breakage that would lead to data loss the patient appeared and also some participants expressed concerns about storage/secure access to data emerged. *"Important to restrict data access and to select the recipients"*. Also, to be careful on interpretation problems or data well collected as *"errors are inherent in the technology, calibration, accuracy aspects..."*

Q9 - Confidence in healthcare recommendations based on digital devices data

Going one step further, when we asked participants whether they would be **confident with recommendations/decisions based on computerized calculations of their data if this would help doctors in their decisions**, **74.77%** say yes. In the interviews, we saw that they trusted the results and decisions as long as they were supervised by a specialist. 16.82% would directly trust this type of decision/recommendation without the need for any other type of supervision, as they considered that there was a prior development already sufficient in which specialists had to be involved.

3.2 Would you be confident in a healthcare decision/recommendations based on a computer calculation using formula of your data?

| | Answers | Ratio |
|--|---------|---------|
| I refuse such a use | 11 | 3.3 % |
| I am afraid about such a use | 12 | 3.6 % |
| I accept such use if as a means to help the physician in the decisions | 249 | 74.77 % |
| I fully trust it | 56 | 16.82 % |
| No Answer | 5 | 1.5 % |

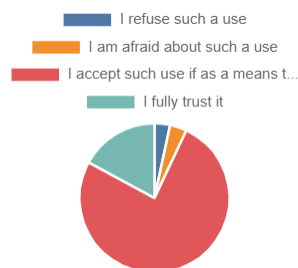


Figure 16

- *Germany*: This is the country where participants indicated the highest acceptance on decision made on computer calculations if this helped physicians (85.19%). Participants from *other Spanish speaking* countries had the highest percentage of confidence in decisions based on calculations, they fully trusted it (27.78%). They were also the ones with the highest percentage of participants afraid of such a use (8.33%).
- Participants *under 65* was the age group were the participants trusted most strongly decisions based on computer calculations (19.44%). Although 80.70% of people between 76-85 accepted such use if helped physicians, there was a low percentage (7.02%) that were most likely to indicate that they rejected this use. Those *over 85* were the ones who were most afraid of this use of data (20%) although 80% indicated that they would accept such use if helped physicians.
- 77.27% of *female* participants said to accept such use if helped physicians. However, they rejected such a use (4.55%) more than men. The group of *men* was the one that showed the highest percentage in trusting decisions based on computer calculation (19.46%).
- Participants with *Secondary school* studies were the ones who accepted such use the most if it helped physicians (80.77%). Participants with *non-formal education* were the ones who trusted decisions based on computer calculation the most (30%). Participants with *PhD's degree* were the ones who indicated in major percentage to be afraid about such a use (12.50%). Also, to refuse such a use (7.50%).

| 3.2 Confidence decision based on computer calculation | France | % | Germany | % | Spain | % | Other | % |
|---|-----------|----------------|-----------|----------------|------------|----------------|-----------|----------------|
| I refuse such a use | 1 | 1,79% | 1 | 3,70% | 9 | 4,21% | 0 | 0,00% |
| I am afraid about such a use | 2 | 3,57% | 0 | 0,00% | 7 | 3,27% | 3 | 8,33% |
| I accept such use if helps physicians | 45 | 80,36% | 23 | 85,19% | 159 | 74,30% | 22 | 61,11% |
| I fully trust it | 8 | 14,29% | 3 | 11,11% | 35 | 16,36% | 10 | 27,78% |
| No answer | 0 | 0,00% | 0 | 0,00% | 4 | 1,87% | 1 | 2,78% |
| TOTAL | 56 | 100,00% | 27 | 100,00% | 214 | 100,00% | 36 | 100,00% |

Table 54 – Confidence on data-based recommendations per country

| 3.2 Confidence decision based on computer calculation | Under 65 | % | 65-75 | % | 76-85 | % | Over 85 | % |
|---|------------|----------------|------------|----------------|-----------|----------------|----------|----------------|
| I refuse such a use | 3 | 1,85% | 4 | 3,70% | 4 | 7,02% | 0 | 0,00% |
| I am afraid about such a use | 5 | 3,09% | 4 | 3,70% | 2 | 3,51% | 1 | 20,00% |
| I accept such use if helps physicians | 121 | 74,69% | 78 | 72,22% | 46 | 80,70% | 4 | 80,00% |
| I fully trust it | 31 | 19,14% | 21 | 19,44% | 4 | 7,02% | 0 | 0,00% |
| No answer | 2 | 1,23% | 1 | 0,93% | 1 | 1,75% | 0 | 0,00% |
| TOTAL | 162 | 100,00% | 108 | 100,00% | 57 | 100,00% | 5 | 100,00% |

Table 55 – Confidence on data-based recommendations per age

| 3.2 Confidence decision based on computer calculation | Female | % | Male | % |
|---|------------|----------------|------------|----------------|
| I refuse such a use | 5 | 4,55% | 5 | 2,26% |
| I am afraid about such a use | 4 | 3,64% | 8 | 3,62% |
| I accept such use if helps physicians | 85 | 77,27% | 163 | 73,76% |
| I fully trust it | 13 | 11,82% | 43 | 19,46% |
| No answer | 3 | 2,73% | 2 | 0,90% |
| TOTAL | 110 | 100,00% | 221 | 100,00% |

Table 56 – Confidence on data-based recommendations per gender

| 3.2 Confidence decision based on computer calculation | No formal education | | Primary school | | Secondary school | | Post-secondary school | | Master degree | | PhD's degree | |
|---|---------------------|----------------|----------------|----------------|------------------|----------------|-----------------------|----------------|---------------|----------------|--------------|----------------|
| | | % | | % | | % | | % | | % | | % |
| I refuse such a use | 0 | 0,00% | 0 | 0,00% | 2 | 3,85% | 4 | 3,67% | 2 | 1,94% | 3 | 7,50% |
| I am afraid about such a use | 0 | 0,00% | 0 | 0,00% | 1 | 1,92% | 3 | 2,75% | 3 | 2,91% | 5 | 12,50% |
| I accept such use if helps physicians | 6 | 60,00% | 15 | 78,95% | 42 | 80,77% | 82 | 75,23% | 79 | 76,70% | 25 | 62,50% |
| I fully trust it | 3 | 30,00% | 4 | 21,05% | 7 | 13,46% | 18 | 16,51% | 18 | 17,48% | 6 | 15,00% |
| No answer | 1 | 10,00% | 0 | 0,00% | 0 | 0,00% | 2 | 1,83% | 1 | 0,97% | 1 | 2,50% |
| TOTAL | 10 | 100,00% | 19 | 100,00% | 52 | 100,00% | 109 | 100,00% | 103 | 100,00% | 40 | 100,00% |

Table 57 – Confidence on data-based recommendations per academic education

During the interviews, participants indicated us:

- Generally, they were positive and confident in a healthcare decision/recommendation based on a computer calculation (e.g., *“Mathematics and logic are based on algorithms and you have to rely on them, it is necessary”; “The more data are collected, the more confident in the medical decision based on them”*) although they thought *“It would be better if such a decision/recommendation was made/supervised by expert staff whose judgement we could trust; human presence of the team remains essential”*.
- *“Dangerous to rely only on data to interpret, need the presence of the person for full reliability”*.
- *“Data should be contextualized (activity/patient state when collected, ...)”*.
- According to many patients, the technology was not developed enough to acquire enough data to make an interpretation and having the maximum amount of information was essential.

Some remarkable comments were:

- *“I trust the technology for a start, and I also believe that this decision would be filtered by the doctor”; “it is the way to detect e.g., falls, blockages, etc.”*
- *“At first, I would take it with a grain of salt, I’m more of a human intervention kind of guy”*
- *“It would take several different measurements to be able to make comparisons and then generate a medical recommendation or decision”*.
- *“I do not think that is going to be as personalized as an orientation done by a real person”*.

Q10 - Importance of control over data sharing

Regarding the importance for the participants of **being able to select the type of data that can be collected with the devices**, **70.87% considered it very/moderately important** for them while 22.52% indicated that it was not important for them and 6.31% were not sure.

3.3 How important is it to you to have the option to select (e.g. switch on/off) which data are collected by digital devices (i.e., smartphone, tablet, computer, specific wearable device –gait sensor on a shoe)?

| | Answers | Ratio |
|----------------------|---------|---------|
| Very important | 136 | 40.84 % |
| Moderately important | 100 | 30.03 % |
| Not important | 46 | 13.81 % |
| Mixed feelings | 21 | 6.31 % |
| Not at all | 29 | 8.71 % |
| No Answer | 1 | 0.3 % |

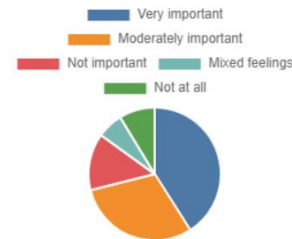


Figure 17

- *German* participants were the ones who considered it most important to be able to select the type of data collected through the devices (62.96%), mostly if they were male and with master's degree. Participants from *other Spanish-speaking countries* were the most likely to say that it was not important to them at all (16.67%).
- Those participants *between 65-75* and *over 85* considered the choice of data selection as very important or moderately important. Compared to other age groups, the group of *76-85 ages* reflects those with more doubts having mixed feelings (14.04%).
- 46.36% [51/110] of *female* participants considered very important to have a selection option, more than *men* (31.22%). There was also a higher percentage of men than women who thought it was not necessary (11.31%).
- People with *non-formal education* were the ones who indicated the importance of being able to select data (50%) the most. And those with *post-secondary school* responded to a greater extent that they did not think it was important (11.93%).

| 3.3 Importance of data selection option | France | % | Germany | % | Spain | % | Other | % |
|---|-----------|----------------|-----------|----------------|------------|----------------|-----------|----------------|
| Very important | 22 | 39,29% | 17 | 62,96% | 80 | 37,38% | 17 | 47,22% |
| Moderately important | 15 | 26,79% | 8 | 29,63% | 67 | 31,31% | 10 | 27,78% |
| Not important | 10 | 17,86% | 2 | 7,41% | 31 | 14,49% | 3 | 8,33% |
| Mixed feelings | 6 | 10,71% | 0 | 0,00% | 15 | 7,01% | 0 | 0,00% |
| Not at all | 3 | 5,36% | 0 | 0,00% | 20 | 9,35% | 6 | 16,67% |
| No answer | 0 | 0,00% | 0 | 0,00% | 1 | 0,47% | 0 | 0,00% |
| TOTAL | 56 | 100,00% | 27 | 100,00% | 214 | 100,00% | 36 | 100,00% |

Table 58 – Control on data collection per country

| 3.3 Importance of data selection option | Under 65 | % | 65-75 | % | 76-85 | % | Over 85 | % |
|---|------------|----------------|------------|----------------|-----------|----------------|----------|----------------|
| Very important | 67 | 41,36% | 48 | 44,44% | 20 | 35,09% | 1 | 20,00% |
| Moderately important | 47 | 29,01% | 31 | 28,70% | 19 | 33,33% | 3 | 60,00% |
| Not important | 21 | 12,96% | 16 | 14,81% | 8 | 14,04% | 1 | 20,00% |
| Mixed feelings | 8 | 4,94% | 5 | 4,63% | 8 | 14,04% | 0 | 0,00% |
| Not at all | 19 | 11,73% | 8 | 7,41% | 1 | 1,75% | 0 | 0,00% |
| No answer | 0 | 0,00% | 0 | 0,00% | 1 | 1,75% | 0 | 0,00% |
| TOTAL | 162 | 100,00% | 108 | 100,00% | 57 | 100,00% | 5 | 100,00% |

Table 59 – Control on data collection per age

| 3.3 Importance of data selection | | | | |
|----------------------------------|------------|----------------|------------|----------------|
| option | Female | % | Male | % |
| Very important | 51 | 46,36% | 85 | 38,46% |
| Moderately important | 30 | 27,27% | 69 | 31,22% |
| Not important | 15 | 13,64% | 30 | 13,57% |
| Mixed feelings | 9 | 8,18% | 12 | 5,43% |
| Not at all | 4 | 3,64% | 25 | 11,31% |
| No answer | 1 | 0,91% | 0 | 0,00% |
| TOTAL | 110 | 100,00% | 221 | 100,00% |

Table 60 – Control on data collection per gender

| 3.3 Importance of data selection option | No formal education | | Primary school | | Secondary school | | Post-secondary school | | Master degree | | PhD's degree | |
|---|---------------------|----------------|----------------|----------------|------------------|----------------|-----------------------|----------------|---------------|----------------|--------------|----------------|
| | | % | | % | | % | | % | | % | | % |
| Very important | 5 | 50,00% | 8 | 42,11% | 27 | 51,92% | 38 | 34,86% | 39 | 37,86% | 19 | 47,50% |
| Moderately important | 3 | 30,00% | 4 | 21,05% | 13 | 25,00% | 34 | 31,19% | 34 | 33,01% | 12 | 30,00% |
| Not important | 2 | 20,00% | 4 | 21,05% | 5 | 9,62% | 18 | 16,51% | 14 | 13,59% | 3 | 7,50% |
| Mixed feelings | 0 | 0,00% | 3 | 15,79% | 2 | 3,85% | 6 | 5,50% | 6 | 5,83% | 4 | 10,00% |
| Not at all | 0 | 0,00% | 0 | 0,00% | 4 | 7,69% | 13 | 11,93% | 10 | 9,71% | 2 | 5,00% |
| No answer | 0 | 0,00% | 0 | 0,00% | 1 | 1,92% | 0 | 0,00% | 0 | 0,00% | 0 | 0,00% |
| TOTAL | 10 | 100,00% | 19 | 100,00% | 52 | 100,00% | 109 | 100,00% | 103 | 100,00% | 40 | 100,00% |

Table 61 – Control on data collection per academic education

| EDUCATION | | | |
|-----------------------|-----------------------|-----------------------|------------|
| COUNTRY | Q10 | Frecuencia | Porcentaje |
| France | Mixed feelings | Master degree | 1 16,7 |
| | | PhD's degree | 1 16,7 |
| | | Post-secondary school | 4 66,7 |
| | | Total | 6 100,0 |
| | Moderately important | Master degree | 4 26,7 |
| | | PhD's degree | 1 6,7 |
| | | Post-secondary school | 9 60,0 |
| | | Secondary school | 1 6,7 |
| | | Total | 15 100,0 |
| | Not at all | Master degree | 1 33,3 |
| Post-secondary school | | 1 33,3 | |
| Secondary school | | 1 33,3 | |
| Total | | 3 100,0 | |
| Not important | Master degree | 3 30,0 | |
| | PhD's degree | 2 20,0 | |
| | Post-secondary school | 5 50,0 | |
| | Total | 10 100,0 | |
| Very important | Master degree | 9 40,9 | |
| | PhD's degree | 2 9,1 | |
| | Post-secondary school | 9 40,9 | |
| | Secondary school | 2 9,1 | |
| | Total | 22 100,0 | |

| EDUCATION | | | |
|-----------|----------------------|-----------------------|------------|
| COUNTRY | Q10 | Frecuencia | Porcentaje |
| Other | Moderately important | Master degree | 3 30,0 |
| | | PhD's degree | 2 20,0 |
| | | Post-secondary school | 4 40,0 |
| | | Secondary school | 1 10,0 |
| | | Total | 10 100,0 |
| | Not at all | Master degree | 3 50,0 |
| | | Post-secondary school | 3 50,0 |
| | | Total | 6 100,0 |
| | Not important | Master degree | 1 33,3 |
| | | Post-secondary school | 2 66,7 |
| | | Total | 3 100,0 |
| | Very important | Master degree | 7 41,2 |
| | | No formal education | 2 11,8 |
| | | PhD's degree | 1 5,9 |
| | | Post-secondary school | 3 17,6 |
| | | Secondary school | 4 23,5 |
| | | Total | 17 100,0 |

| | | | | EDUCATION | | | | |
|---------|-----------------------|-----------------------|-----------------------|------------|------------|--|--|--|
| COUNTRY | Q10 | | | Frecuencia | Porcentaje | | | |
| Germany | Moderately important | Master degree | 2 | 25,0 | | | | |
| | | No formal education | 2 | 25,0 | | | | |
| | | PhD's degree | 1 | 12,5 | | | | |
| | | Post-secondary school | 1 | 12,5 | | | | |
| | | Secondary school | 2 | 25,0 | | | | |
| | | Total | 8 | 100,0 | | | | |
| | | Not important | Secondary school | 2 | 100,0 | | | |
| | | Very important | Master degree | 8 | 47,1 | | | |
| | | | PhD's degree | 1 | 5,9 | | | |
| | | | Post-secondary school | 2 | 11,8 | | | |
| | | | Secondary school | 6 | 35,3 | | | |
| | | | Total | 17 | 100,0 | | | |
| | Other | Moderately important | Master degree | 3 | 30,0 | | | |
| | | | PhD's degree | 2 | 20,0 | | | |
| | | | Post-secondary school | 4 | 40,0 | | | |
| | | | Secondary school | 1 | 10,0 | | | |
| | | | Total | 10 | 100,0 | | | |
| | | Not at all | Master degree | 3 | 50,0 | | | |
| | | | Post-secondary school | 3 | 50,0 | | | |
| | | | Total | 6 | 100,0 | | | |
| | | Not important | Master degree | 1 | 33,3 | | | |
| | | | Post-secondary school | 2 | 66,7 | | | |
| | | | Total | 3 | 100,0 | | | |
| | | Very important | Master degree | 7 | 41,2 | | | |
| | | | No formal education | 2 | 11,8 | | | |
| | | | PhD's degree | 1 | 5,9 | | | |
| | | | Post-secondary school | 3 | 17,6 | | | |
| | | | Secondary school | 4 | 23,5 | | | |
| | | | Total | 17 | 100,0 | | | |
| Spain | Mixed feelings | Secondary school | 1 | 100,0 | | | | |
| | | Master degree | 5 | 33,3 | | | | |
| | | PhD's degree | 3 | 20,0 | | | | |
| | | Post-secondary school | 2 | 13,3 | | | | |
| | | Primary school | 3 | 20,0 | | | | |
| | | Secondary school | 2 | 13,3 | | | | |
| | | Total | 15 | 100,0 | | | | |
| | | Moderately important | Master degree | 25 | 37,3 | | | |
| | | | No formal education | 1 | 1,5 | | | |
| | | | PhD's degree | 8 | 11,9 | | | |
| | | | Post-secondary school | 20 | 29,9 | | | |
| | | | Primary school | 4 | 6,0 | | | |
| | | | Secondary school | 9 | 13,4 | | | |
| | | | Total | 67 | 100,0 | | | |
| | | Not at all | Master degree | 6 | 30,0 | | | |
| | | | PhD's degree | 2 | 10,0 | | | |
| | | | Post-secondary school | 9 | 45,0 | | | |
| | | | Secondary school | 3 | 15,0 | | | |
| | | | Total | 20 | 100,0 | | | |
| | | Not important | Master degree | 10 | 32,3 | | | |
| | | | No formal education | 2 | 6,5 | | | |
| | | | PhD's degree | 1 | 3,2 | | | |
| | | | Post-secondary school | 11 | 35,5 | | | |
| | | | Primary school | 4 | 12,9 | | | |
| | | | Secondary school | 3 | 9,7 | | | |
| | | | Total | 31 | 100,0 | | | |
| | | Very important | Master degree | 15 | 18,8 | | | |
| | No formal education | | 3 | 3,8 | | | | |
| | PhD's degree | | 15 | 18,8 | | | | |
| | Post-secondary school | | 24 | 30,0 | | | | |
| | Primary school | | 8 | 10,0 | | | | |
| | Secondary school | | 15 | 18,8 | | | | |
| | | Total | 80 | 100,0 | | | | |

Table 62 – Control on data collection per country and academic education

We have extracted some comments from the participants **during the interviews**:

- *“I think it is very important that we could decide when to collect the data, even what data to collect”; “It is important to be able to differentiate and choose the private sphere from the non-private sphere”; It is important to keep control over the type of data shared and who it is shared with (e.g., Problems induced for bank loans when some health data are known); “I think it is important, in fact we are part of an investigation and we should also intervene in the treatment of the devices”.*
- But they also took into account the negative aspects of being able to select data collection: *“It is important for my privacy but in the end it depends on what is needed for the study”; “I don't really care, but since you're using a device set up to collect health data, I think everything it collects is important”; It is in the general interest to open to the public the sharing of one's data”; “This would distort the data in the conclusions and we would not arrive at a reliable and real solution”; “I see a small drawback and that is to be able to switch it on or to know if it is collecting the data again”.*

Even so, we met a number of patients who told us that:

- *“The patient wouldn't be able to choose which data is the most relevant, considers the doctor must be the one choosing to process only relevant data”.*

APPEARANCE OF DATA

Q11 - Importance of instructions

Regarding **instructions**, a very high percentage (**81.68%**) considered that **having them would increase their willingness to use digital devices**.

4.1 Would having instructions increase your willingness to use digital devices (i.e., smartphone, tablet, computer, specific wearable device –gait sensor on a shoe) that collect health data?

| | Answers | Ratio |
|-------------|---------|---------|
| Yes | 272 | 81.68 % |
| No | 20 | 6.01 % |
| I am unsure | 36 | 10.81 % |
| No Answer | 5 | 1.5 % |

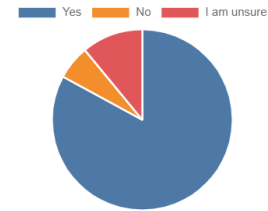


Figure 18

- The percentage of participants from *Spain* who thought that instructions would help the use of technology was the highest of all (83.64%). Although the percentage of those who say no was low, it was the highest of all countries (14%). The highest rate of participants who were not sure what to answer were from *Germany* (18.52%).
- Most participants *under 65* thought that the instructions helped (80.86%) but it was also this group in which the highest proportion of participants indicated that instructions would not increase usage (8.02%). *Between 65-75* slightly more people considered that instructions would increase the use of digital devices (84.26%). Although 80% of participants *over 85* considered instructions to increase digital devices use, 20% considered that they were not important.
- By gender there are no significant differences although men seemed to agree more. Slightly more *men* than *women* perceived that having instructions would increase the use of devices (82.35%).
- The group of *non-formal education* participants least agreed that having instructions would increase the use of digital devices (60%). Those were also the participants more insecure about given an answer to this question (40%).
- The group of *primary school studies* was the one that most agreed in which having instructions will increase the use of digital devices (94.74%). Also, 82% of participants with *secondary school* studies considered that instructions would encourage the use of devices. In the *PhD's degree* group, the percentage of those who are unsure about instructions and use of devices is slightly increased compared with other groups (7.50%).

| 4.1 Instructions increase use digital devices | France | % | Germany | % | Spain | % | Other | % |
|---|-----------|----------------|-----------|----------------|------------|----------------|-----------|----------------|
| Yes | 42 | 75,00% | 22 | 81,48% | 179 | 83,64% | 29 | 80,56% |
| No | 5 | 8,93% | 0 | 0,00% | 13 | 6,07% | 2 | 5,56% |
| Unsure | 8 | 14,29% | 5 | 18,52% | 19 | 8,88% | 4 | 11,11% |
| No answer | 1 | 1,79% | 0 | 0,00% | 3 | 1,40% | 1 | 2,78% |
| TOTAL | 56 | 100,00% | 27 | 100,00% | 214 | 100,00% | 36 | 100,00% |

Table 63 – Importance of instructions per country

| 4.1 Instructions increase use digital devices | Under 65 | % | 65-75 | % | 76-85 | % | Over 85 | % |
|---|------------|----------------|------------|----------------|-----------|----------------|----------|----------------|
| Yes | 131 | 80,86% | 91 | 84,26% | 46 | 80,70% | 4 | 80,00% |
| No | 13 | 8,02% | 4 | 3,70% | 2 | 3,51% | 1 | 20,00% |
| Unsure | 16 | 9,88% | 12 | 11,11% | 8 | 14,04% | 0 | 0,00% |
| No answer | 2 | 1,23% | 1 | 0,93% | 1 | 1,75% | 0 | 0,00% |
| TOTAL | 162 | 100,00% | 108 | 100,00% | 57 | 100,00% | 5 | 100,00% |

Table 64 – Importance of instructions per age

| 4.1 Instructions increase use digital devices | Female | % | Male | % |
|---|------------|----------------|------------|----------------|
| Yes | 88 | 80,00% | 182 | 82,35% |
| No | 7 | 6,36% | 13 | 5,88% |
| Unsure | 13 | 11,82% | 23 | 10,41% |
| No answer | 2 | 1,82% | 3 | 1,36% |
| TOTAL | 110 | 100,00% | 221 | 100,00% |

Table 65 – Importance of instructions per gender

| 4.1 Instructions increase use digital devices | No formal education | | Primary school | | Secondary school | | Post-secondary school | | Master degree | | PhD's degree | |
|---|---------------------|----------------|----------------|----------------|------------------|----------------|-----------------------|----------------|---------------|----------------|--------------|----------------|
| | | % | | % | | % | | % | | % | | % |
| Yes | 6 | 60,00% | 18 | 94,74% | 43 | 82,69% | 78 | 71,56% | 93 | 90,29% | 34 | 85,00% |
| No | 0 | 0,00% | 0 | 0,00% | 3 | 5,77% | 10 | 9,17% | 5 | 4,85% | 2 | 5,00% |
| Unsure | 4 | 40,00% | 1 | 5,26% | 5 | 9,62% | 19 | 17,43% | 4 | 3,88% | 3 | 7,50% |
| No answer | 0 | 0,00% | 0 | 0,00% | 1 | 1,92% | 2 | 1,83% | 1 | 0,97% | 1 | 2,50% |
| TOTAL | 10 | 100,00% | 19 | 100,00% | 52 | 100,00% | 109 | 100,00% | 103 | 100,00% | 40 | 100,00% |

Table 66 – Importance of instructions per academic situation

During the interviews, most participants indicated us that having instructions:

- Probably it would make easier to use and handle any technology (*“as technology is usually something that fails a lot”*) and this would make it more appealing increasing their willingness to use devices.

Some of their comments were:

- “Yes, it is clear that if someone/something helps you, you are encouraged to try new things”; “I would use them anyway but if you give me instructions, I will use them”.*
- For others: *“It would not increase my willingness to use the technology but if I have the need to use it, of course I would like to have”; “I would not increase my willingness to use it because for me it is not necessary and I would use them anyway. Sometimes the instructions are too generic or too complex”; “In principle, yes, although I can handle myself without any problems”.*

Q12 - Type of instructions preferred

As for the type of instructions, what they told us during interviews was that if they cannot be real people face to face, then video explainers featuring **real people (57.66%)** followed by written manuals (43.24%), animated videos (36.64%) and at a greater distance pop-up message (17.72%).

4.2 If yes, what type of instructions would you prefer? (you can select more than one option if you like)

| | Answers | Ratio |
|--------------------|---------|---------|
| Animation videos | 122 | 36.64 % |
| Real person videos | 192 | 57.66 % |
| Written manuals | 144 | 43.24 % |
| Pop up messages | 59 | 17.72 % |
| No Answer | 16 | 4.8 % |

Figure 19

- *French* participants and *other Spanish speakers from other countries* preferred real person videos (39.29% and 38.46%) together with animation videos (37.50% and 25.64% respectively). *German* participants preferred pop up messages (37.04%) and written manuals (25.93%). *Spanish* participants also preferred real person videos (36.92%) and written manuals (31.31%).
- Results were very similar in different age groups preferring in all of them real person videos compared to other options.
- Regarding gender results were also similar although pop-up messages were preferred by *females* (13.64%) more than *males* (9.05%).
- Per academic education: The group with *non-formal education* had the highest percentage of preference for real person videos (40%). *PhD's degree* was the group with the highest percentage of preference for animation videos (27.50%) and *Master's degree* group the one for pop-up messages (14.56%).

| 4.2 Type of instructions preferred | France | % | Germany | % | Spain | % | Other | % |
|------------------------------------|-----------|----------------|-----------|----------------|------------|----------------|-----------|----------------|
| Animation videos | 21 | 37,50% | 4 | 14,81% | 45 | 21,03% | 10 | 25,64% |
| Real person videos | 22 | 39,29% | 6 | 22,22% | 79 | 36,92% | 15 | 38,46% |
| Written manuals | 9 | 16,07% | 7 | 25,93% | 67 | 31,31% | 7 | 17,95% |
| Pop up messages | 3 | 5,36% | 10 | 37,04% | 17 | 7,94% | 4 | 10,26% |
| No answer | 1 | 1,79% | 0 | 0,00% | 6 | 2,80% | 3 | 7,69% |
| TOTAL | 56 | 100,00% | 27 | 100,00% | 214 | 100,00% | 39 | 100,00% |

Table 67 – Preference on instructions per country

| 4.2 Type of instructions preferred | Under 65 | % | 65-75 | % | 76-85 | % | Over 85 | % |
|------------------------------------|------------|----------------|------------|----------------|-----------|----------------|----------|----------------|
| Animation videos | 35 | 21,60% | 27 | 25,00% | 12 | 21,05% | 1 | 20,00% |
| Real person videos | 59 | 36,42% | 44 | 40,74% | 20 | 35,09% | 2 | 40,00% |
| Written manuals | 45 | 27,78% | 27 | 25,00% | 18 | 31,58% | 1 | 20,00% |
| Pop up messages | 19 | 11,73% | 7 | 6,48% | 6 | 10,53% | 0 | 0,00% |
| No answer | 4 | 2,47% | 3 | 2,78% | 1 | 1,75% | 1 | 20,00% |
| TOTAL | 162 | 100,00% | 108 | 100,00% | 57 | 100,00% | 5 | 100,00% |

Table 68 – Preference on instructions per age

| 4.2 Type of instructions preferred | Female | % | Male | % |
|------------------------------------|------------|----------------|------------|----------------|
| Animation videos | 25 | 22,73% | 55 | 24,89% |
| Real person videos | 36 | 32,73% | 84 | 38,01% |
| Written manuals | 29 | 26,36% | 58 | 26,24% |
| Pop up messages | 15 | 13,64% | 20 | 9,05% |
| No answer | 5 | 4,55% | 4 | 1,81% |
| TOTAL | 110 | 100,00% | 221 | 100,00% |

Table 69 – Preference on instructions per gender

| 4.2 Type of instructions preferred | No formal education | | Primary school | | Secondary school | | Post-secondary school | | Master degree | | PhD's degree | |
|------------------------------------|---------------------|----------------|----------------|----------------|------------------|----------------|-----------------------|----------------|---------------|----------------|--------------|----------------|
| | | % | | % | | % | | % | | % | | % |
| Animation videos | 2 | 20,00% | 5 | 26,32% | 18 | 18,56% | 23 | 21,10% | 22 | 21,36% | 11 | 27,50% |
| Real person videos | 4 | 40,00% | 7 | 36,84% | 38 | 39,18% | 42 | 38,53% | 34 | 33,01% | 13 | 32,50% |
| Written manuals | 3 | 30,00% | 6 | 31,58% | 24 | 24,74% | 25 | 22,94% | 31 | 30,10% | 13 | 32,50% |
| Pop up messages | 1 | 10,00% | 1 | 5,26% | 14 | 14,43% | 13 | 11,93% | 15 | 14,56% | 2 | 5,00% |
| No answer | 0 | 0,00% | 0 | 0,00% | 3 | 3,09% | 6 | 5,50% | 1 | 0,97% | 1 | 2,50% |
| TOTAL | 10 | 100,00% | 19 | 100,00% | 97 | 100,00% | 109 | 100,00% | 103 | 100,00% | 40 | 100,00% |

Table 70 – Preference on instructions per academic situation

Regarding the type of instructions participants would prefer to receive, **during the interviews** we got the following feedback:

- The vast majority preferred instructions given by a person, face to face *“I prefer a real person to help me, although if I have a clear video, it is also a good option”; “I prefer a real person to help me, and if they send me a manual by email that would be perfect”; “I prefer it to be a real person because nowadays there is a tendency not to explain things or to relate little to people”; “I would prefer a real person, although the other options are also suitable”; “It is important to maintain a contact with humans When answers are robotized, the questions/answers are limited, sometimes not very accurate, without nuances”; “Oral instructions but no robotized voice (« ok google » type)”.*
- Written instructions would then follow: *“Anything can be useful, but I prefer a written manual in any case”; “Oral instructions first, then written instructions to bring home”.*
- Then animated videos, graphics and pop-ups: *“For me the most convenient option is the video tutorials”; “I prefer animation videos, because then I can watch it as many times as necessary”; “I prefer pop-up messages; they are more immediate and shorter”.*
- In any case, they said diversity was important, also to provide visual information, practical and simple. *“A good option is showing testimonies of people, which are interesting but can also be anxiety-provoking. What is important is to de-dramatize”.*

Q13 - Importance of motivational messages

On receiving motivational messages, **67.87% thought that they would be useful or very useful when using devices**. While 23.12% thought that those would not influence their motivation, and 8.41% have mixed feelings.

4.3 And what about motivational messages, would encourage you to use digital devices (e.g. “you are doing very well – please keep up”)?

| | Answers | Ratio |
|----------------|---------|---------|
| Very much | 107 | 32.13 % |
| It can be nice | 119 | 35.74 % |
| Not so much | 45 | 13.51 % |
| Mixed feelings | 28 | 8.41 % |
| Not at all | 32 | 9.61 % |
| No Answer | 2 | 0.6 % |

Figure 20

- Participants from *other Spanish speaking countries* were those that said that to receive motivational messages was very important for them or nice to receive (83.33%). French participants were the group with the highest percentage, 33.93%, that considered that not so much or not at all.
- People *over 85* gave the greatest importance to motivational messages (40%) while those younger, *under 65* gave the least importance to them.
- 40% of *females* thought that receiving motivational messages could be nice, a higher rate than *men* (33.94%). Women were slightly more hesitant than men regarding this question.
- As for academic education, people with *non-formal education* (20%), *primary school* (57.89%) and also *secondary school* (34.62%), showed highest percentages when it came to thinking that it could be nice to receive motivational messages (60% [6/10]). Those with *Master's degree* (10.68%) and *PhD's degree* (45%) thought most strongly that receiving motivational messages would not encourage the use of digital devices at all.

| 4.3 Motivational messages to encourage use digital devices | France | % | Germany | % | Spain | % | Other | % |
|--|-----------|----------------|-----------|----------------|------------|----------------|-----------|----------------|
| Very much | 11 | 19,64% | 8 | 29,63% | 70 | 32,71% | 18 | 50,00% |
| It can be nice | 15 | 26,79% | 1 | 3,70% | 90 | 42,06% | 12 | 33,33% |
| Not so much | 8 | 14,29% | 3 | 11,11% | 32 | 14,95% | 2 | 5,56% |
| Mixed feelings | 11 | 19,64% | 13 | 48,15% | 2 | 0,93% | 2 | 5,56% |
| Not at all | 11 | 19,64% | 2 | 7,41% | 18 | 8,41% | 1 | 2,78% |
| No answer | 0 | 0,00% | 0 | 0,00% | 2 | 0,93% | 1 | 2,78% |
| TOTAL | 56 | 100,00% | 27 | 100,00% | 214 | 100,00% | 36 | 100,00% |

Table 71 – Importance of motivational messages per country

| 4.3 Motivational messages to encourage use digital devices | Under 65 | % | 65-75 | % | 76-85 | % | Over 85 | % |
|--|------------|----------------|------------|----------------|-----------|----------------|----------|----------------|
| Very much | 52 | 32,10% | 40 | 37,04% | 13 | 22,81% | 2 | 40,00% |
| It can be nice | 57 | 35,19% | 39 | 36,11% | 21 | 36,84% | 2 | 40,00% |
| Not so much | 23 | 14,20% | 10 | 9,26% | 11 | 19,30% | 1 | 20,00% |
| Mixed feelings | 13 | 8,02% | 8 | 7,41% | 7 | 12,28% | 0 | 0,00% |
| Not at all | 17 | 10,49% | 10 | 9,26% | 5 | 8,77% | 0 | 0,00% |
| No answer | 0 | 0,00% | 1 | 0,93% | 0 | 0,00% | 0 | 0,00% |
| TOTAL | 162 | 100,00% | 108 | 100,00% | 57 | 100,00% | 5 | 100,00% |

Table 72 – Importance of motivational messages per age

| 4.3 Motivational messages to encourage use digital devices | Female | % | Male | % |
|--|------------|----------------|------------|----------------|
| Very much | 29 | 26,36% | 76 | 34,39% |
| It can be nice | 44 | 40,00% | 75 | 33,94% |
| Not so much | 16 | 14,55% | 29 | 13,12% |
| Mixed feelings | 11 | 10,00% | 17 | 7,69% |
| Not at all | 9 | 8,18% | 23 | 10,41% |
| No answer | 1 | 0,91% | 1 | 0,45% |
| TOTAL | 110 | 100,00% | 221 | 100,00% |

Table 73 – Importance of motivational messages per gender

| 4.3 Motivational messages to encourage use digital devices | No formal education | | Primary school | | Secondary school | | Post-secondary school | | Master degree | | PhD's degree | |
|--|---------------------|----------------|----------------|----------------|------------------|----------------|-----------------------|----------------|---------------|----------------|--------------|----------------|
| | | % | | % | | % | | % | | % | | % |
| Very much | 2 | 20,00% | 11 | 57,89% | 18 | 34,62% | 31 | 28,44% | 38 | 36,89% | 7 | 17,50% |
| It can be nice | 6 | 60,00% | 4 | 21,05% | 17 | 32,69% | 39 | 35,78% | 35 | 33,98% | 18 | 45,00% |
| Not so much | 1 | 10,00% | 2 | 10,53% | 6 | 11,54% | 17 | 15,60% | 12 | 11,65% | 7 | 17,50% |
| Mixed feelings | 1 | 10,00% | 2 | 10,53% | 6 | 11,54% | 11 | 10,09% | 7 | 6,80% | 4 | 10,00% |
| Not at all | 0 | 0,00% | 0 | 0,00% | 4 | 7,69% | 10 | 9,17% | 11 | 10,68% | 4 | 10,00% |
| No answer | 0 | 0,00% | 0 | 0,00% | 1 | 1,92% | 1 | 0,92% | 0 | 0,00% | 0 | 0,00% |
| TOTAL | 10 | 100,00% | 19 | 100,00% | 52 | 100,00% | 109 | 100,00% | 103 | 100,00% | 40 | 100,00% |

Table 74 – Importance of motivational messages per academic education

Regarding motivational messages, **during the interviews** we got the following feedback from participants:

- In general terms they are welcome among the participants: “Yes, because encouragement is always a good thing”; “I think it’s perfect, you always like to be told if you’re doing well”; “Yes, of course I would be encouraged by the motivational messages to continue using the devices”; “It would be good; I think it would increase the willingness to use the technology”; “It is very important that someone tells you if you are doing it right because sometimes with new things, I get a bit desperate when I don’t understand how it works and even don’t understand the instructions, so these messages reassure you”; “Yes, getting motivated is very important: Examples given of a star reward when 10 000 steps per day reached, ‘you are half way through’ ‘In progress’ ‘you have reached the target’.
- Very important, daily encouragement needed. Example given of an application used by one patient where he can share data/performance in real time with community (running app shared with).
- However, we are also told that: “Sometimes they are very paternalistic, infantilizing”. “If the motivational messages are robotized or kept very general (in opposition with personalized messages), it is not very interesting. It is better to get personalized messages of motivation”.
- And some patients said they did not like them: “I don’t like them because I am already predisposed to use them and it would be annoying to keep warning me all the time”; “I don’t see any need for them. I motivate myself by just doing things”; “For me it is not useful”.
- They generally mention that usually no feedback is given in the research process either motivational messages. Regrets regarding the lack of information and feedback on data collected.

8. CONCLUSIONS

e-Health, telemedicine and other digital technologies such as 4G/5G mobile communications, artificial intelligence and supercomputing offer new opportunities to transform healthcare systems¹⁶. They allow the capture, management and processing of large volumes of diverse data generated from multiple sources to create new knowledge. They enable new approaches to personalised medicine, accelerating scientific progress, early diagnosis and prevention of diseases and more effective treatments.

But there is a digital divide between generations in terms of access and use of modern Information and Communications Technologies (ICTs); such technologies typically include mobile telephones, personal computers, the Internet and related services.

In 2017, almost one third (31 %) of the EU-28 adult population had above basic digital skills: the shares for older people were much lower, at 16 % for those aged 55-64 years and 7 % for people aged 65-74 years. Moreover, some groups of people were likely to have less access to Internet than others such as care home residents and some people knew how to use it but were wary of it¹⁷. However, given the continuing digitalisation of society and an increasing number of tech savvy people (and others with some ICT skills) passing into older age, people are likely to make far greater use of ICTs in the future.

The study we have carried out, within the framework of DIGIPD project, has reflected the above. We have found a profile of participant with Parkinson's disease willing to be part of the change towards the digital health and care. Patients are awaiting this transformation and they agree to access to their own health data, to share their health data if privacy and security are ensured and to provide feedback on quality of treatments, as this infographic from the European Commission shows:

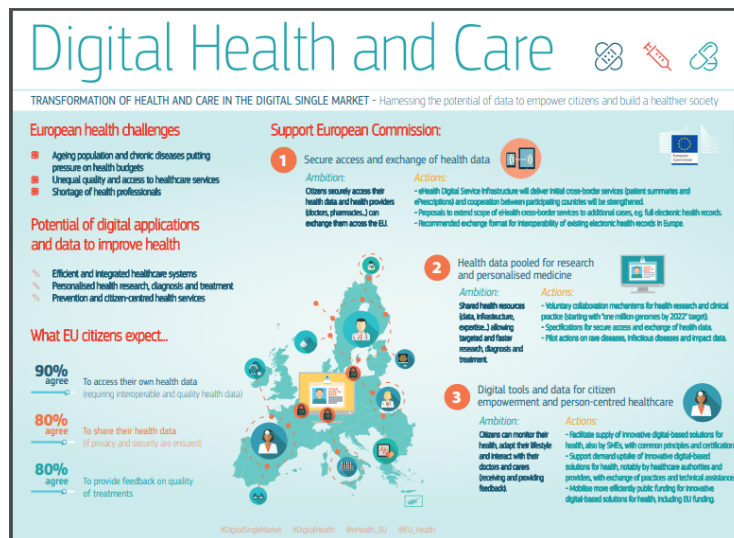


Figure 21 - Infographic Digital Health and Care in the EU © European Commission

¹⁶ Health and care has been identified by most of the digital Public-Private Partnerships in Horizon 2020 as a core business area where digital technologies can play a major role. The Digitising European Industry (DEI) high level group recently established a working group on health. The profound transformation of the job market sees an increasing number of routine tasks being replaced by automated processes, but at same time it leads to opportunities multiplying in the digital healthcare sector (Deloitte 2016 Transformers: How machines are changing every sector of the economy)

¹⁷ Beresford 2019

During May to October 2022, 333 participants were interviewed in France, Germany and Spain and indicated us that they wanted to collaborate using digital devices if this would improve the information that their health and social care teams had about their health.

This feedback was even from those who had never used devices to monitor aspects of health before. We have seen that there is a generalized predisposition to follow the steps indicated by their health and social care teams in this use with the support of instructions and motivational messages.

As far as those concerns in the use we have not encountered many, being their main requirements:

- Devices to be familiar (e.g., smartphones), simple and intuitive.
- With a design easy to use and understand, regardless of the user's experience, knowledge, skills or concentration level.
- Also, flexible to accommodate a wide range of individual preferences and to minimize hazards and the adverse consequences of accidental or unintended actions.
- Requiring low physical effort so that can be usable efficiently and comfortably and with minimum fatigue.

All of these factors have coincided with the approach known as "*Design for all*", that means considering the needs and requirements of people at the ends of the population continuum rather than just those in the middle. This, in order to ensure that mainstream equipment and services can be used by a wide range of users, including older people and those with disabilities.

Participants also reported to feel confidence and accepted the use of sensitive data for a better personalized treatment of Parkinson's Disease indicating that they were in favour of any innovation in data collection that would help doctors in their decisions. The level of acceptance showed was proportional to the medical benefit they perceived. Indeed, most of the question's patients asked interviewers during the sessions were about reliability, accuracy of AI solutions and its potential usefulness (key determinants of the "*Technology Acceptance Model (TAM)*¹⁸") more than about the use of devices itself.

EU policies consistently emphasise the importance of digital solutions such as eHealth stressing how digital innovations can improve integration of care through up-to-date information channels and deliver more targeted, personalised, effective and efficient healthcare, reducing errors and length of hospitalisation. To allow citizens to assume responsibility for their health by using digital solutions, such as wearables and mHealth¹⁹ apps, we need to engage them.

To achieve this we must provide them, among other things, with information about the need to participate in data research studies. In addition, they should be informed in their own words about the studies in which they participate and be given regular feedback on what is being developed thanks to their participation and data in order to resolve any doubts and achieve sustainable participation of citizens.

"I think these interviews are very important because I believe that the patient has to be involved from the beginning, to be able to decide when it is appropriate to collect data and that the data is put to good use."

(Feedback from a patient during an interview in this study)

¹⁸ Or et al., 2006; Or and Karsh, 2009

¹⁹ Mobile Health (mHealth) is a sub-segment of eHealth and covers medical and public health practice supported by mobile devices. It especially includes the use of mobile communication devices for health and well-being services and information purposes as well as mobile health applications. See COM (2014) 219 (http://ec.europa.eu/newsroom/dae/document.cfm?doc_id=5147)

9. ANNEXES

In the following, we provide as Annex 1 the guidelines and links for the online survey. In Annex 2 the guidelines and templates (informed consents, questions and transcription sheets) to be used by the researchers for the preparation of the interviews can be found.

ANNEX 1: ONLINE SURVEY

PRIVACY STATEMENT

Project description

DIGIPD is a European research project that aims to assess to what extent data about health extracted from digital devices (i.e., smartphone, tablet, computer, specific wearable device –gait sensor on a shoe), could aid accurate disease diagnosis and treatment for each individual patient. This could help make better informed medical decisions at the right time.

Informed consent

We invite you to participate in this online survey. Before deciding whether you wish to participate, it is important that you understand why this interview is being conducted, what it involves, as well as your rights. Please read this information carefully and feel free to discuss it with the DIGIPD team if you wish. Please feel free to ask any questions or if you need more information, email Mayca Marin at investigacion@parkinsonmadrid.org

Who are we?

DIGIPD consortium, acting as the data controller, is made up of partners from different EU countries. In this specific study, the coordinator is Asociación Parkinson Madrid (APM).

What is the purpose of this survey?

With the widespread usage of digital devices (i.e., smartphone, tablet, computer, specific wearable device –gait sensor on a shoe) it is also possible to gather useful information about your health status (even at home and more frequently) that can be combined with other data to help practitioners in order to better adapt (personalize) the medical treatment that you receive.

The primary objective of this survey, that takes no more than 15 minutes to complete, is to collect detailed information on the opinions, thoughts, experiences and feelings of patients affected by PD, on the use of this health data extracted from digital devices in clinical routine.

The secondary objective is to take into account those responses gathered to better adapt DIGIPD data acquisition procedures to patients' demands.

What do we want you to do?

If you agree to take part in this survey, you will be asked about the use of health data extracted from digital devices (i.e., smartphone, tablet, computer, specific wearable device –gait sensor on a shoe). You will also be asked about your experience(s) and preference(s) with sensing devices and/or applications for activity and/or behaviour tracking through an online questionnaire.

Please, do not include any private health information or any other information that you would not feel comfortable to share publicly in your responses.

Your feedback is very valuable to us, as it will help us to improve our work.

What information are we collecting?

The categories of personal data that we process are the following:

- Socio-demographic data: country of residence; age; gender; level of education; diagnosis; type of housing and need for a carer or not.
- All information provided through the survey: opinion(s) and experience(s) about digital devices and procedures to obtain data, acceptance and appearance on the use of data. You may choose not to answer certain questions if you wish.
- Any additional information that you want to communicate to DIGIPD team.

How will we use this information?

During and after the study, we will store all your responses from the questionnaires digitally, without including any information that identifies you and with restricted access to DIGIPD team members only.

Your data will be processed and analysed by APM for the purposes of investigating the acceptance of the use of sensitive personal data by PD patients for personalized medicine.

Information from the study may also be presented at formal meetings, public forums, conferences, and in journal papers. Questionnaire responses will also be made available online to other members of the Consortium. You will not be identified or identifiable in any of these presentations, publications, and data files.

What is the lawfulness basis for processing?

As regards the abovementioned purposes, your data is processed on the lawfulness basis of your consent (art. 6.1.a GDPR + art. 9.2.a GDPR).

What are the potential benefits of participating?

This study will give you the chance to reflect on your frequent doubts, preferences and/or your experience related with the spread of digital devices (i.e., smartphone, tablet, computer, and specific wearable device –gait sensor on a shoe).

The knowledge gained from this survey will help us understand how people see the collection and use of their personal data for their health care process.

Are there any risks involved?

There are no physical risks associated with taking part in this online survey.

What if you no longer want to take part?

Participation in this survey is voluntary. You can terminate at any time without incurring any disadvantages.

What about security/confidentiality?

Your privacy and confidentiality are important. The following procedures will be used to protect the confidentiality of any form of data you provide:

- Your responses documented in digital forms such as word processor files, spreadsheets, databases etc. In the present survey, full anonymity is not guaranteed as regards the questions that will be

asked and the selection of participants. Therefore, we apply the GDPR and request the informed consent of the participants.

-Study findings will be presented in a summary format and you will not be identified.

-We will use an encrypted electronic data store with secure authentication for the research data.

What are your rights, under the limits of the GDPR??

You have the following rights:

- ✓ Right to withdraw your consent for data processing. By not clicking on the "Send" button at the end of this questionnaire, you withdraw your participation and your previous answers will not be saved, will be deleted and will not be evaluated;
- ✓ Right of access, at reasonable intervals, including the right to know whether DIGIPD processes your data;
- ✓ Right to obtain, at reasonable intervals, a copy of your personal data undergoing processing, provided that it does not adversely affects the rights and freedoms of others;
- ✓ Right to rectification of your personal data;
- ✓ Right to object to processing of your personal data;
- ✓ Right to restriction of processing of your personal data;
- ✓ Right to erasure of your personal data;
- ✓ Right to data portability;
- ✓ Right to lodge a complaint with the Data Protection Authority:

Agencia Española de Protección de Datos

www.aepd.es/es

C/ Jorge Juan, 6. 28001 - Madrid

Tel.: +34 91 266 35 17

You can lodge a complaint with APM at subdireccioneconomica@parkinsonmadrid.org

If you have any other questions, please feel free to ask the research team through an e-mail: investigacion@parkinsonmadrid.org

Cookies

As many other websites, we use cookies to collect data. A cookie is a small file which is stored on your computer (More information here: https://ec.europa.eu/info/cookies_en)

QUESTIONS

1. Socio-demographics

We want to know some of the characteristics of the population we are reaching (e.g., age, diagnosis). This will enable us to differentiate answers between different sub-groups, offering us insights that otherwise would be missed.

| | |
|---|--|
| 1.1 Which country are you living? | <ol style="list-style-type: none"> 1. France 2. Germany 3. Spain 4. Other |
| 1.2 What is your age (in years)? | <ol style="list-style-type: none"> 1. Under 65 2. 65-75 3. 76-85 4. Over 85 |
| 1.3 Which is your gender? | <ol style="list-style-type: none"> 1. Male 2. Female 3. Intersex |
| 1.4 Which is your highest academic education? | <ol style="list-style-type: none"> 1. PhD's degree 2. Master degree 3. Post -secondary school 4. Secondary school 5. Primary school 6. No formal education |
| 1.5 Which is your main diagnosis? | <ol style="list-style-type: none"> 1. Parkinson's disease 2. Other |
| 1.6 How long has it been since your diagnosis? | <ol style="list-style-type: none"> 1. Just diagnosed 2. Between 1-5 3. Between 6-10 4. Between 11-15 5. Between 16-20 6. Over 20 years ago |
| 1.7 Do you have a caregiver? | <ol style="list-style-type: none"> 1. No need a carer 2. Informal carer (i.e., relative, neighbour, friend) 3. Formal carer (i.e., support assistant, nurse) 4. Other |
| 1.8 What type of housing do you live in? | <ol style="list-style-type: none"> 1. At home 2. At home and temporary in care (i.e., day care) 3. In residential care 4. Other |

2. DIGIPD devices and procedures

We would like to know your preferences and concerns regarding different procedures and digital devices that may be used in the DIGIPD project. In this way, we will be able to better adjust to your needs and requirements as a user.

| | |
|---|--|
| <p>2.1 Have you ever used digital devices that collect process and/or display personal data to help you detect aspects of your health? (i.e., smartphone, tablet, computer, specific wearable device –gait sensor on a shoe)</p> | <ol style="list-style-type: none"> 1. Yes 2. No 3. I am unsure |
| <p>2.2 Would you use digital devices (i.e., smartphone, tablet, computer, specific wearable device –gait sensor on a shoe) if this would improve the information that your health care team has about you?</p> | <ol style="list-style-type: none"> 1. Yes 2. No 3. I am unsure |
| <p>2.3 Would any of the following factors concern you if using them? (you can select more than one option, if you like)</p> | <ol style="list-style-type: none"> 1. Too time-consuming 2. Not be able to handle the device, even with support 3. Not willing to share your health data with anyone 4. Not concerned about any of these factors and happy to use them 5. Other |
| <p>2.4 Which of the following digital devices would you like to use better? (you can select more than one option, if you like)</p> | <ol style="list-style-type: none"> 1. Headset microphone 2. Computer microphone and webcam 3. Smartphone 4. Sensors on the shoe 5. None of them |
| <p>2.5 If you were to use them, how would you prefer to do it?</p> | <ol style="list-style-type: none"> 1- At home, on a regular basis (i.e., daily) 2- At home, when necessary (i.e., monthly) 3- At periodical hospital visits 4- Either option if needed 5- None of them |
| <p>2.6 What would be a convenient duration of a data collection session for you?</p> | <ol style="list-style-type: none"> 1. >15 minutes 2. 15-30 minutes 3. 30 minutes-1 hour 4. I do not mind 5. Whatever the doctor-expert says |
| <p>2.7 If you were using a digital device for the purpose of extracting data to inform professionals about your health status, would you also like to receive some feedback (i.e., report on the results of data collection)?</p> | <ol style="list-style-type: none"> 1. Yes 2. No 3. I am unsure |

3. Acceptance of the use of data in DIGIPD

Through the use of digital devices (i.e., smartphone, tablet, computer, specific wearable device –gait sensor on a shoe) it is possible to gather information about your health status that can be combined with other data to help practitioners in order to better adapt (personalize) the medical treatment that you receive. In this respect, we would like to hear your opinion:

| | |
|---|---|
| <p>3.1 Would you accept the use of your physical or mental state data, gathered through digital devices (i.e., smartphone, tablet, computer, specific wearable device –gait sensor on a shoe), for your medical treatment and health care purposes?</p> | <ol style="list-style-type: none"> 1. Yes 2.No 3.I am unsure |
| <p>3.2 Would you be confident in a healthcare decision/recommendations based on a computer calculation using formula of your data?</p> | <ol style="list-style-type: none"> 1. I refuse such use 2. I am afraid about such use 3. I accept such use if helps the physician in the diagnostic 4. I fully trust it |
| <p>3.3 How important is it to you to have the option to select (e.g., switch on/off) which data are collected by digital devices (i.e., smartphone, tablet, computer, specific wearable device – gait sensor on a shoe)?</p> | <ol style="list-style-type: none"> 1. Very 2. Moderately 3. Little 4. Mixed feelings 5. Not at all |

4. Appearance of data in DIGIPD

Our design's usability depends on how well its features accommodate to users' needs and contexts. For this reason, we would like to receive your response on the following questions:

| | |
|---|--|
| <p>4.1 Would having instructions increase your willingness to use digital devices (i.e., smartphone, tablet, computer, specific wearable device –gait sensor on a shoe) that collect health data?</p> | <ol style="list-style-type: none"> 1. Yes 2. No 3.I am unsure |
| <p>4.2 If yes, what type of instructions would you prefer? (you can select more than one option if you like)</p> | <ol style="list-style-type: none"> 1.Animation videos 2.Real person videos 3.Written manuals 4.Pop up messages |

4.3 And what about **motivational messages**, would encourage you to use digital devices (i.e., “you are doing very well – please keep up”)?

1. Very much
2. It can be nice
3. Not so much
4. Mixed feelings
5. Not at all

ANNEX 2: TELEMATHIC INTERVIEWS

1.1 Conduction guide

An interview is an information-gathering technique particularly useful for getting in-depth information around a topic (e.g., acceptance for use of sensitive data). It is essentially a kind of conversation between a researcher/s and a participant/s.

In the next lines a guide approach is intended to ensure that the same general areas of information are collected from each interviewee and we gather comparable data; this provides more focus than the conversational approach, but through open-ended questions we will still allow the respondent a degree of freedom to choose how to answer a question, and adaptability in getting information from the interviewee.

These interviews will be used alongside visual methods (e.g., video recording, photographs) and observation to ensure all partners stay on track with precise questions but also broad ones.

Interviews preparation

- First, translate the interview template into your own language. This way you will not lose the meaning of the question (along with information that the interviewee may provide) at the time of the interview.
- It is preferable to do a test interview before interviewing the patients. Read all questions carefully, to keep clear focus on the intention, and test the environment. Also think about the kinds of things that the participant might want to talk about his/her health, needs, technology experience and acceptance, current market situation, etc.
- For some questions, think about how you can make the question clearer, or how it may be easier to answer.
- Add some time before the conversation. Leaving a few moments before starting helps the interviewee to adapt and normalize the situation. This is partly to do with ethics but also partly to striking up some kind of relationship with the person that you are going to be interviewing, so that they feel that you are someone that they trust (with their stories or their information).
- Choose a setting with the fewest distraction. Avoid loud lights or noises, ensure the interviewee is comfortable (you might ask them if they are), etc. Often, they may feel more comfortable at their own places of work, rehabilitation or homes.
- Explain the purpose of the interview and explain what the information will be used for, within the project.
- Address terms of the free and voluntary nature of the participation.
- Remind the interviewee that they don't have to say or register their name. The interview and the recording will start only after verbal approval from them and the interviewers.
- Note any terms of confidentiality. Explain who will get access to their answers and how their answers will be stored and analysed. It is the researcher's responsibility to protect interview participants and the information they provide. Let them know the confidentiality of their identity and that they can withdraw from the interview anytime they want. Informed consent and information sheet will be provided and signed at this point.
- Explain the format of the interview. Explain the type of interview you are conducting and its nature. If you want them to ask questions, specify if they're to do so as they have them or wait until the end of the interview.
- Indicate how long the interview usually takes.
- Tell them how to get in touch with you later if they want to.

- Ask them if they have any questions before you both get started with the interview.
- Don't count on your memory to recall their answers. Ask for permission to record the interview, take pictures and/or bring along someone to take notes.

Sequence of questions

- Get the respondents involved in the interview as soon as possible.
- Questions should be asked one at a time.
- Before asking about personal matters, first ask about some facts (e.g., activities planned for the day). With this approach, respondents can more easily engage in the interview before warming up to more personal matters.
- We have tried to mix closed-ended questions with open-ended questions throughout the interview to avoid long lists of fact-based questions, which tends to leave respondents disengaged.
- The last questions might be to allow respondents to provide any other information they prefer to add and their impressions of the interview.

Conducting interviews

- Occasionally verify your recording tools (e.g., camera, voice recorder) are working.
- Ask one question at a time.
- We should listen carefully to the response of the participant.
- Attempt to remain as neutral as possible. That is, don't show strong emotional reactions to their responses. Try to act as if "you've heard it all before."
- Encourage responses with occasional nods of the head, "uh huh", etc. Remember we want to obtain specific data but also significant personal information.
- Do not try to predict what kinds of responses we might get.
- Be careful about the appearance when note taking. That is, if you jump to take a note, it may appear as if you're surprised or very pleased about an answer, which may influence answers to future questions.
- Provide transition between major topics, e.g., "we've been talking about (some topic) and now I'd like to move on to (another topic)."
- Don't lose control of the interview. This can occur when respondents stray to another topic, take so long to answer a question that time begins to run out, or even begin asking questions to the interviewer.

Immediately after interviews

- Verify if your recording tools, if used, worked throughout the interview.
- Make any notes on your written notes, e.g., to clarify any scratchings; ensure pages are numbered; fill out any notes that don't make sense; etc.
- Write down any observations made during the interview. You will find an "additional information sheet" just after each interview template, to be filled by you for this purpose. Remember that this information will be analysed as well.

1.2 Conduction template

PRIVACY STATEMENT

Project description

DIGIPD is a European research project that aims to assess to what extent data about health extracted from digital devices (i.e., smartphone, tablet, computer, specific wearable device –gait sensor on a shoe), could aid accurate disease diagnosis and treatment for each individual patient. This could help make better informed medical decisions at the right time.

Informed consent

We invite you to participate in this interview by phone/face to face. Before deciding whether you wish to participate, it is important that you understand your rights, why this interview is being conducted and what it involves. Please read this information carefully and feel free to discuss it with DIGIPD team if you wish. Please feel free to ask any questions or if you need more information, email Mayca Marin at investigacion@parkinsonmadrid.org

Who are we?

DIGIPD consortium, acting as the data controller, is made up of partners from different EU countries. In this specific study, the coordinator is Asociación Parkinson Madrid (APM).

What is the purpose of this interview?

With the widespread usage of digital devices (i.e., smartphone, tablet, computer, specific wearable device –gait sensor on a shoe) it is also possible to gather useful information about your health status (even at home and more frequently) that can be combined with other data to help practitioners in order to better adapt (personalize) the medical treatment that you receive.

The primary objective of this survey, that takes no more than 15 minutes to complete, is to collect detailed information on the opinions, thoughts, experiences and feelings of patients affected by PD, on the use of this health data extracted from digital devices in clinical routine.

The secondary objective is to take into account those responses gathered to better adapt DIGIPD data acquisition procedures to patients' demands.

What do we want you to do?

If you agree to take part in this interview, you will be asked about the use of health data extracted from digital devices (i.e., smartphone, tablet, computer, and specific wearable device –gait sensor on a shoe). You will also be asked about your experience(s) and preference(s) with sensing devices and/or applications for activity and/or behaviour tracking.

Please, do not include any private health information or any other information that you would not feel comfortable to share publicly in your responses.

Your feedback is very valuable to us, as it will help us to improve the study design.

What information are we collecting?

The categories of personal data that we process are the following:

- Socio-demographic data: country of residence; age; gender; level of education; diagnosis; type of housing and need for a carer or not.
- All information provided through the interview: opinion(s) and experience(s) about devices and procedures to obtain data, acceptance and appearance on the use of data. You may choose not to answer to certain questions if you wish.
- Any additional information that you want to communicate to DIGIPD Team.

How will we use this information?

During and after the interview, we will store all your responses in paper and then digitally, without including any information that identifies you and with restricted access to DIGIPD team members only.

Your data will be kept pseudo-anonymised in the organisation that collects your information (ICM – French patients); UKE – German patients; APM – Spanish patients) and in an anonymised form in the organisation that processes and analyses it, APM, for the purposes of analysing the acceptance of the use of sensitive personal data by PD patients for personalized medicine.

Information from the study may also be presented at formal meetings, public forums, conferences, and in journal papers. Interview responses will also be made available online to other members of the Consortium. You will not be identified in any of these presentations, publications, and data files.

What is the lawfulness basis for processing?

As regards the abovementioned purposes, your data is processed on the lawfulness basis of your consent (art. 6.1.a GDPR + art. 9.2.a GDPR).

What are the potential benefits of participating?

This study will give you the chance to reflect on your frequent doubts, preferences and/or your experience related with the spread of digital devices (i.e., smartphone, tablet, computer, specific wearable device –gait sensor on a shoe).

The knowledge gained from this interview will help us understand how people see the collection and use of their personal data for their health care process.

Are there any risks involved?

There are no physical risks associated with taking part in this interview by phone/ face-to-face.

What if you no longer want to take part?

Participation in this interview is voluntary. You can terminate at any time without incurring any disadvantages.

What about security/confidentiality?

Your privacy and confidentiality are important. The following procedures will be used to protect the confidentiality of any form of data you provide:

-Your responses will be documented in digital forms such as word processor files, spreadsheets, databases etc. Full anonymity is not guaranteed as regards the questions that will be asked and the selection of participants. Therefore, we apply the GDPR and request the informed consent of the participants.

-Study findings will be presented in a summary format and you will not be identified.

-We will use an encrypted electronic data store with secure authentication for the research data.

What are your rights, under the limits of the GDPR?

You have the following rights:

- Right to withdraw your consent for data processing;
- Right of access, at reasonable intervals, including the right to know whether DIGIPD processes your data;
- Right to obtain, at reasonable intervals, a copy of your personal data undergoing processing, provided that it does not adversely affects the rights and freedoms of others;
- Right to rectification of your personal data;
- Right to object to processing of your personal data;
- Right to restriction of processing of your personal data;
- Right to erasure of your personal data;
- Right to data portability;
- Right to lodge a complaint with the Data Protection Authority

Agencia Española de Protección de Datos

www.aepd.es/es

C/ Jorge Juan, 6. 28001 - Madrid

Tel.: +34 91 266 35 17

You can lodge a complaint with APM at subdireccioneconomica@parkinsonmadrid.org

If you have any other questions, please feel free to ask the research team through an e-mail:
investigacion@parkinsonmadrid.org

QUESTIONS

| | |
|---|--|
| Interview centre (indicate: ICM, UKE or APM) | |
| Date | |

📎 Before starting the interview have a look to the “Guide for interviews”. At this point is when the interviewer has to explain the interviewee the purpose of the interview, what the information will be used for, those terms of the free and voluntary nature of the participation, confidentiality, etc. Informed consent and information sheets would be signed before starting asking questions.

Thank you for participating in this research,

| |
|--|
| Do you have any questions before we start? |
| |

Now, we would like to know more about you:

1. Socio-demographics

We want to know some of the characteristics of the population we are reaching (e.g., age, diagnosis). This will enable us to differentiate answers between different sub-groups, offering us insights that otherwise would be missed.

| | |
|---|--|
| 1.1 Country | <ol style="list-style-type: none"> 1. France 2. Germany 3. Spain |
| 1.2 Interviewee's age (in years) | <ol style="list-style-type: none"> 1. Under 65 2. 65-75 3. 76-85 4. Over 85 |
| 1.3 Interviewee's biological sex | <ol style="list-style-type: none"> 1. Male 2. Female 3. Intersex |
| 1.4 Interviewee's highest academic education | <ol style="list-style-type: none"> 1. PhD's degree 2. Master degree 3. Post -secondary school 4. Secondary school 5. Primary school 6. No formal education |
| 1.5 Interviewee's main diagnose | <ol style="list-style-type: none"> 1- Parkinson's disease 2- Specify another: |
| 1.6 Years since the diagnosis | <ol style="list-style-type: none"> 1. Just diagnosed 2. Between 1-5 3. Between 6-10 |

| | |
|--|--|
| | <ul style="list-style-type: none"> 4. Between 11-15 5. Between 16-20 6. Over 20 years ago |
| 1.7 Caregivers of the interviewee | <ul style="list-style-type: none"> 1. No need a carer 2. Informal carer (e.g., relative, neighbour, friend) 3. Formal carer (e.g., support assistant, nurse) 4. Specify another: |
| 1.8 Household type | <ul style="list-style-type: none"> 1. At home 2. At home and temporary in care (e.g. day care) 3. In residential care 4. Other |

2. DIGIPD devices and procedures

We would like to know your preferences and concerns regarding different procedures and digital devices that may be used in the DIGIPD project. In this way, we will be able to better adjust to your needs and requirements as a user.

2.1 Have you **ever used digital devices** that collect process and/or display personal data to help you detect aspects of your health? (i.e., smartphone, tablet, computer, specific wearable device –gait sensor on a shoe) / Explore reasons and feelings behind

2.1 **Would you use** digital devices (i.e., smartphone, tablet, computer, specific wearable device – gait sensor on a shoe) if this would improve the information that your health care team has about you? / Explore reasons and feelings behind

2.3 Would you be **concerned** about any factors, when considering using digital devices (i.e., smartphone, tablet, computer, specific wearable device –gait sensor on a shoe)? (Try to see if time consuming, handling the devices, etc., would be concerns) /Explore reasons and feelings behind (e.g., what would make those worries go away: assistance, instructions, family members present...)

2.4 Are there some **digital devices you would prefer to use** over others? (See if the person prefers the most used ones or/and if they interested in the latest ones on the market). Make use of some images of DIGIPD devices to see how they participant feels about them (i.e., headset microphone, computer webcam, smartphone, sensors on the shoe...)

2.5 **How** would you prefer to use them? In periodically hospital visits / at home on regular basis / at home when necessary? What advantages and disadvantages do you see in each of those uses? Why?

2.6 What would be a **convenient duration** of a data collection session for you? (e.g., >15 minutes /1 hour/ Whatever the doctor-expert says)

2.7 If you were using a device for the purpose of extracting data to inform professionals about your health status, would you also like to receive some **feedback**? / Explore reasons and feelings behind

3. Acceptance of the use of data in DIGIPD

Through the use of digital devices (i.e., smartphone, tablet, computer, specific wearable device –gait sensor on a shoe) it is possible to gather information about your health status that can be combined with other data to help practitioners in order to better adapt (personalize) the medical treatment that you receive. In this respect, we would like to hear your opinion:

3.1 Would you accept the use of your physical or mental state **data, gathered through digital devices** (i.e., smartphone, tablet, computer, specific wearable device –gait sensor on a shoe), for your medical treatment and health care purposes? / Explore reasons and feelings behind

3.2 Would you be confident in a healthcare **decision/recommendation based on a computer calculation using formula** of your data? / Explore reasons and feelings behind

3.3 How important is it to you to have the option to **select** (e.g., switch on/off) which **data** are **collected** by digital devices (i.e., smartphone, tablet, computer, specific wearable device –gait sensor on a shoe)? / Explore reasons and feelings behind

4. Appearance of data in DIGIPD

Our design's usability depends on how well its features accommodate to users' needs and contexts. For this reason, we would like to ask you the following questions:

4.1 Would having **instructions** increase your willingness to use digital devices (i.e., smartphone, tablet, computer, specific wearable device –gait sensor on a shoe) that collect health data? / Explore reasons behind

4.2 If yes, what **type** of instructions do you prefer? / Explore if Animation videos; Real person videos; Written manuals; Pop up messages...

4.3 And what about **motivational messages**, would encourage you to use digital devices (e.g., "you are doing very well – please keep up")? / Explore reasons behind

5. Closing the interview

| |
|---|
| 5.1 Do you want to add any other information and/or impression of the interview? |
| |

Thank you for participating in this interview!

6. Additional information to be filled by the interviewer

| |
|---|
| 6.1 Physical context description (e.g., where did the interview occur and when? What were the interviewees and interviewer disposition in the room? Anybody else was present?) |
| |

| |
|--|
| 6.2 Psychological elements present in the interview (e.g., were the interviewees particularly nervous at any time? How was their general mood? Did you appreciate a positive interaction with you? Did you appreciate difficulties regarding following the conversation?) |
| |

| |
|---|
| 6.3 Non-verbal aspects (e.g., do people reflect relaxed body positions or on the contrary can we appreciate stress on them while interviewed?) |
| |

| |
|--|
| 6.4 Anecdotes to mention (e.g., were there any surprises during the interview?) |
| |

| |
|--------------------|
| 6.5 Others: |
| |

1.3 Voice and face recording devices (TSP contribution)

Two types of recordings are made: hospital recordings and telephone recordings.

Yearly hospital audio visual recordings (see Figure 1) take place at the ICM (Pitié-Salpêtrière hospital) during the annual visit of the ICEBERG protocol participants. Participants are recorded simultaneously with a professional microphone, the computer microphone and a webcam used for the acquisitions. The recording session lasts 15 to 20 minutes and includes 28 vocal tasks to be performed (readings, repetitions, monologue, etc.). The tasks are explained to the participant through a user interface on Matlab. The professional microphone used to record the participants is the Beyerdynamics Opus 55 mk ii headset microphone and the computer is a MacBook Air. The device used for video recording is a Webcam with integrated encoding and compression of the type 195 Logitech C922 Pro Stream Webcam.

Monthly telephone audio recordings (see Figure 2) take place once a month when participants call an interactive telephone server. The recording session lasts about 12 minutes and includes 20 voice tasks. Participants can use their landline or mobile phone, but must keep the same phone for the duration of the protocol.



Figure 1- Pictures of the professional microphone, the computer and the webcam used for audio visual recordings at the hospital



Figure 2- Example picture of a phone used for telephone recordings

1.4 Transcription guide

Steps to follow

- You can use free software for transcriptions, e.g., Parlatype.
- Use “near literal” transcription:
 - ✓ Don't use your own words, but use the words of the respondents.
 - ✓ If a respondent speaks too fast, use software (see above) to slow down the audio without lowering the tone.
 - ✓ Usual/comprehensible abbreviations are welcome ("bc.", "btw." "w/.")
 - ✓ If you can't understand the respondent write in brackets, what do you think he or she said (expectations are) or (...). The review 2nd person shall comment/improve it.
 - ✓ Words with emphasis are CAPITALIZED.
- And try to:
 - ✓ Make correction of the wording. Make sure that transcripts from your interviews are clear and readable.
 - ✓ Clarify meanings when needed, where appropriate, make fragments into full sentences.
 - ✓ Move text to its appropriate place.
 - ✓ Remove names or identifying information.
- Once you have finished the transcription, translated into English.
- To do so, you can help yourself with software, e.g., DeepL translator: <https://www.deepl.com/translator>

- For quality criteria: one person should do the transcription followed by a revision from another team member.
- Use the templates uploaded in SharePoint to transcribe your interview in text format.
- The order of the questions in this transcript template is the same as in the interview question template.
- In column “B” you will find the categories of our questions.
- All questions are filled in “Column F: Interviewee’s answers”.
- In column “G” you will find a column for the interviewer’s notes and in column “H” another one in case a second person in the organization reviews the data to improve quality.
- The boxes for the answers of the closed questions have a filter to select the answer obtained.
- In the boxes for the answers of open questions, you can write text.
- Use different pages of the Excel document to dump into each the answer of each respondent.
- Upload the Excel document, adding the acronym of your entity at the end, in SharePoint.
- For this purpose, you can open your own folder inside it adding the acronym of your entity at the end.
- Any difficulties, report to APM (Task 5.4 subcontractor) at: investigacion@parkinsonmadrid.org

1.4 Transcription template

It is already uploaded in SharePoint. Ready to be used.

Screenshot:

| Interview with patients | | | | |
|---|----------------------------|-----------------------|---------------------|-------------|
| QUESTIONS / ITEMS | SPECIFICATIONS | INTERVIEWEE'S ANSWERS | INTERVIEWER'S NOTES | OTHER NOTES |
| Interview centre | | | | |
| Date | | | | |
| Do you have any questions before we start? | | | | |
| Now, we would like to know more about you: | | | | |
| 1. Sociodemographic Information | | | | |
| 1.1 Country | Specify another country: | | | |
| 1.2 Interviewee's age (in years) | | | | |
| 1.3 Interviewee's biological sex | | | | |
| 1.4 Interviewee's highest academic education | | | | |
| 1.5 Interviewee's main diagnose | Specify another diagnose: | | | |
| 1.6 Years since the diagnose | | | | |
| 1.7 Caregivers of the interviewee | Specify another caregiver: | | | |
| 1.8 Household type | | | | |
| 2. DIGIPD devices and procedures | | | | |
| 2.1 Have you ever used digital devices that collect process and/or display personal data to help you detect aspects of your health? (i.e., smartphone, tablet, computer, specific wearable device –gait sensor on a shoe) / Explore reasons and feelings behind | | | | |