



**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

SUMMARY OF RESULTS

Acceptance for use of sensitive data to extract digital biomarkers (DMs)

Introduction & justification of the study

- Investigate acceptance of use of sensitive personal data (specifically DMs) by patients for AI driven personalized medicine.

Methodology

- Study over 6 months in France, Germany, & Spain.
- Participants needed to have previous clinical diagnosis of Parkinson's
 - but couldn't be involved if they had significant cognitive impairment, intellectual disability or other serious psychiatric conditions.
- Total sample of patients = 333 people
 - 67 interviews, 266 online surveys.
 - 27 German participants — 27 paper interviews.
 - 56 French participants — 36 online survey + 20 phone interviews.
 - 250 Spanish participants — 20 face-to-face interviews + 194 online surveys from Spain + 36 online surveys from other Spanish speaking countries.

Sociodemographic information

- Country
 - 64% of participants from Spain, 16.82% from France, 8.11% Germany.
 - 10.81% considered to be from other Spanish speaking countries (filled out Spanish version of questionnaire).
- Age
 - 48.65% of participants under 65 years of age, 32.43% in 65-75 age range, 17.12% 76 and over, 1.5% 85 and over.
- Gender
 - 66.37% of participants were men, 33.03% were women — almost twice as many men as women participated.
- Academic education
 - 32.73% of participants had post-secondary school studies, 30.93% had master's degree, 15.62% had secondary school as highest education, and 12.01% had PhD's degree.
- 75.78% of participants have maximum of 10 years since diagnosis.
- 69.37% of participants did not need a caregiver.

Use of digital devices

- 49.55% had never used devices to monitor aspects of health, and 47.75% had.
- Spanish participants under 65 rated highest in use of digital healthcare devices (63.4%).
- regarding education: participants with non-formal education were least likely to use digital health devices (30%), those with PhD's degree most likely (55%).
- 100% of participants over 85 years old had never used digital devices.
- during interviews participants said:
 - They like when smartwatches show steps/calories information and reminders for medication intake.

Willingness to use digital devices

- 83.48% of participants indicated they would be willing to use digital devices if this would improve the information their health & social care teams have about them.
- Regarding age: as age range increased, percentages showed decreasing willingness and increasing doubts.
 - Participants under 65 most likely to use digital devices (89.51%) & had less doubts to do so (3.70%).
 - Participants 65-75 years also willing to use digital devices (80.56%) but had increased doubts (9.26%).
- Regarding gender: older men tend to have more open attitude to digital technologies than older women
 - 84.62% of male participants indicated they would be willing to use digital devices compared to 80.91% of female participants.
- Regarding education: participants with non-formal education indicated least willingness to use digital devices (60%). participants with Master's degree most likely to use digital devices for this purpose (90.29%)
- During interviews, participants said:
 - Would use digital devices if doctors/neurologists could improve patient's care by having data on their health.
 - Having valid digital tools could improve communication with healthcare team
- Participants noted a few constraints to the use of devices:
 - Devices could be intrusive; procedures might require too many skills or too much time.
 - Uncomfortable using or distrusted technology.

Concerns about use of technological devices

- 63.06% of participants said in general they were not worried about their use of technological devices.
- Factors that might be of greater concern to participants:
 - 11.11% reported their use might be too time-consuming, 9.01% feared they would not be able to handle the device, and 5.71% were reluctant to share their health data with other people.
- Spanish participants reported fewest concerns when using technology (71.03%).
- Regarding age: participants under 65 had least concerns about use of technology (69.14%).
 - 60% of participants over 85 are concerned about their ability to use the devices.
- Regarding education: those with non-formal studies most concerned in general, while those with Master's degree had least concerns related to technology use (66.02% not concerned).
- During interviews participants said:
 - In general, they found the use of technology useful and interesting.
 - Technology should be as simple as possible.
 - Concerns about invading their privacy, wearing a device all day, or having difficulties with technology
 - but concerns lessened when it came to data for monitoring their health status

Preference on devices

- Smartphone chosen by most (74.34%), followed by shoe sensor (48.3%).
- Lower degree of acceptance for computer microphone and webcam (27.92%) and headset microphones (18.25%).
- Regarding age: under 65 had highest smartphone preference (51.25%), while those between 65-75 had highest shoe sensor preference (28.70%).
- During interviews participants said:
 - Liked smartwatches for health data, activity data, and sleep.
 - Some felt uncomfortable touching small screens as those were unsuitable for Parkinson's patients.

Preferences on place and frequency of use

- Almost half of participants (48.95%) did not mind how devices are used as long as it was the way indicated by professionals as most optimal.
- Most participants preferred to use it at home (46.25%) rather than during regular hospital visits (17.42%).

- Regarding gender: females showed greater adaptability to the option of use that was needed (50.91%).
- During interviews participants said:
 - Preferred to use devices at home on a regular basis.
 - Collection data at hospital perceived as more hectic and less comfortable.

Preference on duration of data collection sessions

- 37.54% of participants would do whatever the doctor/expert says.
- Convenient duration of active session seems to be between 15-30 minutes (21.02%).
- Regarding age: those over 85 preferred sessions of less than 15 minutes (40%).
- During interviews participants said:
 - If data collection sessions done at home, participants required fewer restrictions — sessions could be longer or continuous.
 - If sessions done at hospital, preferred 30 min to 1 hour each visit.

Preference on feedback

- Almost all participants (94.29%) would like to receive information about their health
- Over 85 showed higher percentage of people indicating they would not like to receive feedback (20%).
- During interviews participants said:
 - It was essential to have regular feedback in terms of data collection and conclusions about their health condition.
 - Not receiving any feedback is demotivating.

Acceptance of use of personal data for treatment/healthcare

- 90.69% of participants would accept the use of their data obtained through digital devices for treatment/health care purposes.
- PhD's degree participants were group with highest percentage of participants not in favour (5%) and with more doubts (12.50%).
- During interviews participants said:
 - Participants would accept such use if performed by medical team that was in charge of patient's follow-up.
 - Recognized the importance of collecting this kind of data to improve or research medical treatments and health care.

Confidence in healthcare recommendations based on digital devices data

- 74.77% of participants would be confident with recommendations/decisions based on computerized calculations of their data if this would help doctors in their decisions
- Participants in Germany indicated highest acceptance on decision made on computer calculations if this helped physicians (85.19%).
- Regarding age: under 65 was the age group that most strongly trusted decisions based on computer calculations (19.44%).
 - Over 85 were most afraid of this use of data (20%), although 80% would accept such use if it helped physicians
- During interviews participants said:
 - Generally positive and confident in healthcare decision/recommendation based on computer calculation.
 - Human presence to make final decision or supervise decision is important.
 - Also feedback that computer calculation decisions might not be as personalized.

Importance of control over data sharing

- 70.87% considered it very/moderately important to be able to select the type of data that can be collected with the devices.
 - 22.52% indicated it was not important.
- German participants considered it most important to be able to select type of data (62.96%), while participants from other Spanish-speaking countries most likely to say it was not important to them at all (16.67%).
- During interviews participants said:
 - Some believed doctors should be the ones choosing which data is the most relevant, not the patient.
 - Others wanted to decide when to collect data and who the data is shared with
 - And others believed selecting data would distort the data and prevent reliable solutions.

Importance of instructions

- Very high percentage (81.68%) considered having instructions would increase their willingness to use digital devices.
- Regarding education: group of non-formal education participants least agreed that having instructions would increase the use of digital devices (60%), while group of primary school studies participants most agreed that instructions would increase their use (94.74%).
- During interviews participants said:

- Instructions would make it easier to use & handle technology, would make using it more appealing.

Type of instructions preferred

- If face to face instruction not possible:
 - Majority prefer video explainers with real people (57.66%), least preferred pop-up messages (17.72%).
- Regarding education: group with non-formal education had strongest preference for real person videos (40%).
- During interviews participants said:
 - Prefer instructions given by person, face to face.
 - Written instructions and practical/simple visual information are helpful.

Importance of motivational messages

- 67.87% thought motivational messages would be (very) useful when using devices.
- Regarding age: people over 85 gave greatest importance to motivational messages (40%) while under 65 gave least importance.
- Regarding education: those with higher degrees (Master's and PhD's) felt motivational messages would not encourage the use of digital devices, while people who had received less education showed highest percentage of wanting those messages.
- During interviews participants said:
 - In general, motivational messages welcome among participants.
 - Could encourage & reassure the use of devices.
 - Motivational messages not helpful if robotized or not personalized.

Conclusions

- Parkinson's patients generally agree to access their own health data, share their health data if privacy/security ensured & to provide feedback on quality of treatments.
- Wanted to collaborate using digital devices if this would improve the information their health/social care teams had about their health.
- Main requirements for their use of devices:
 - Familiar, simple & intuitive devices (i.e., smartphones).
 - Easy to use/understand design regardless of user's familiarity/skills
 - Requires low physical effort.

- All above factors coincide with approach “Design for all” — considering needs/requirements of people at ends of population continuum rather than just those in the middle.