**Supplementary Material**

**Additional File 2 (Tables)**

**Table 1. Test-Retest results: Wilcoxon tests and modified Fleiss' kappa statistic (s\*) with percentile bootstrap confidence intervals**

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Abbreviated item label** | **Z** | **p-values** | **s\*** | **LCL** | **UCL** |
| 14 Receive clear information  | -1.311 | .190 | .749 | .588 | .886 |
| 15 Can ask questions  | -1.232 | .218 | .703 | .543 | .840 |
| 16 Express views  | -0.215 | .830 | .611 | 451 | .749 |
| 17 Involved in discussions  | -0.447 | .655 | .589 | 451 | .726 |
| 18 Involved in decisions  | -0.693 | .488 | .497 | 314 | .680 |
| 19 Type of treatment  | -0.816 | .414 | .863 | 749 | .954 |
| 20 Purpose of treatment  | -0.905 | .366 | .794 | .657 | .909 |
| 21 Side effects  | 0.000 | 1.000 | .817 | .680 | .931 |
| 22 Risks  | -0.513 | .608 | .771 | 611 | .909 |
| 23 Benefits  | -1.232 | .218 | .703 | .520 | .840 |
| 24 Cost-free treatment  | -0.500 | .617 | .680 | .520 | .817 |
| 25 Pain/discomfort  | -0.816 | .414 | 863 | .749 | .954 |
| 26 Quality of life  | -0.632 | .527 | .817 | .680 | .931 |
| 27 Part of medical research  | -1.265 | .206 | .771 | .657 | .886 |
| 28 Understanding trial aim  | -0.243 | .808 | .657 | .520 | .794 |
| 29 Understanding—help you now  | -1.155 | .248 | .726 | .611 | .840 |
| 30 Understanding—help others now  | -1.147 | .251 | .611 | .451 | .749 |
| 31 Understanding—help you in future  | -1.376 | .169 | .520 | .337 | .703 |
| 32 Understanding—help others in future  | -0.471 | .637 | 634 | .497 | .771 |
| 33 Compensation  | -0.786 | .432 | .543 | .360 | .703 |
| 34 Out of pocket costs  | -0.333 | .739 | .794 | .680 | .909 |
| 35 Convenient  | -1.387 | .166 | .749 | .611 | .863 |
| 36 Travel  | -0.881 | .378 | .634 | .451 | .771 |
| 37 Need help in participation  | 0.000 | 1.000 | .589 | .429 | .749 |
| 38 Confidential  | -1.705 | .088 | .680 | .497 | .840 |
| 39 Ethically approved  | 0.000 | 1.000 | .771 | .611 | .909 |
| 40 Person to contact during trial | -0.420 | .675 | .657 | .451 | .817 |

**Table 2. Loadings of items on factors emerging from rotated component matrix**

|  |  |  |
| --- | --- | --- |
| **Abbreviated item label** | **Factors** | **Communalities** |
|  | **Risks and benefits** | **Patient’s expectations** | **Patient’s participation** | **Cost and convenience** |  |
| 22 Risks | .842 |  |  |  | .752 |
| 21 Side effects | .809 |  |  |  | .696 |
| 20 Purpose of treatment | .609 | .400 |  |  | .574 |
| 19 Type of treatment | .590 |  |  |  | .517 |
| 23 Benefits | .557 |  |  |  | .481 |
| 25 Pain/discomfort | .554 |  |  |  | .429 |
| 39 Ethically approved | .490 |  |  |  | .425 |
| 38 Confidential | .475 |  |  |  | .456 |
| 26 P of life | .465 |  |  |  | .340 |
| 40 Person to contact during trial | .453 |  |  |  | .461 |
| 31 Understanding—help you in future |  | .750 |  |  | .630 |
| 29 Understanding—help you now |  | .717 |  |  | .665 |
| 32 Understanding—help others in future |  | .706 |  |  | .583 |
| 28 Understanding trial aim |  | .699 |  |  | .622 |
| 30 Understanding—help others now |  | .693 |  |  | .625 |
| 27 Part of medical research |  | .553 |  |  | .434 |
| 17 Involved in discussions |  |  | .812 |  | .699 |
| 16 Express views |  |  | .796 |  | .657 |
| 18 Involved in decisions |  |  | .765 |  | .629 |
| 15 Can ask questions |  |  | .716 |  | .555 |
| 14 Receive clear information |  |  | .674 |  | .512 |
| 34 Out of pocket costs |  |  |  | .726 | .622 |
| 37 Need help in participation |  |  |  | .678 | .532 |
| 33 Compensation |  |  |  | .639 | .433 |
| 36 Travel |  |  |  | .621 | .497 |
| 35 Convenience |  |  |  | .581 | .556 |

**Table 3. Patient questionnaire subscales (factors) with reliability estimates**

|  |  |  |  |
| --- | --- | --- | --- |
| **Subscales** | **Number of items** | **Cronbach’s alpha** | **Corrected Item-Total Correlation** |
| Risks and benefits  | 10 | .867 | .468-.720 |
| Patient’s expectations  | 6 | .864 | .548-.732 |
| Patient’s participation | 5 | .827 | .535-.725 |
| Cost and convenience | 5 | .770 | .404-.633 |

**Table 4.** Gender

| **Gender** | **Participants**  **(n)** | **Percentage****(%)** |
| --- | --- | --- |
| Male | 161 | 51.4 |
| Female | 152 | 48.6 |
| **Total** | **313** | **100.0** |

**Table 5.** Education level

| **Education level** | **Participants**  **(n)** | **Percentage (%)** |
| --- | --- | --- |
| Secondary school | 9 | 2.9 |
| High school | 103 | 32.9 |
| Higher education | 155 | 49.5 |
| Master’s degree | 41 | 13.1 |
| Doctorate | 5 | 1.6 |
| **Total** | **313** | **100.0** |

**Table 6.** Marital status

| **Marital status** | **Participants**  **(n)** | **Percentage (%)** |
| --- | --- | --- |
| Married / In cohabitation | 198 | 63.3 |
| Single / Divorced / Widowed | 115 | 36.7 |
| **Total** | **313** | **100.0** |

**Table 7.** Race

| **Race** | **Participants**  **(n)** | **Percentage (%)** |
| --- | --- | --- |
| White | 306 | 97.8 |
| Hispanic and Latino | 2 | 0.6 |
| Asian  | 1 | 0.3 |
| Other | 4 | 1.3 |
| **Total** | **313** | **100.0** |

**Table 8.** Employment status

| **Employment status** | **Participants****(n)** | **Percentage (%)** |
| --- | --- | --- |
| Working / Self-employed | 196 | 62.6 |
| Housekeeping | 23 | 7.3 |
| Disabled | 2 | 0.6 |
| Retired | 32 | 10.2 |
| Unemployed | 39 | 12.5 |
| Student | 21 | 6.7 |
| **Total** | **313** | **100.0** |

**Table 9.** Personal annual income

| **Income status** | **Participants****(n)** | **Percentage (%)** |
| --- | --- | --- |
| 0 to 10 000 euros | 149 | 47.6 |
| 10 000 to 20 000 euros | 101 | 32.3 |
| 20 000 to 30 000 euros | 41 | 13.1 |
| 30 000 to 50 000 euros | 18 | 5.8 |
| 50 000 to 80 000 euros | 2 | 0.6 |
|  Higher than 80 000 euros | 2 | 0.6 |
| **Total** | **313** | **100.0** |

**Table 10.** Mode of transport to research site

| **Mode of transport** | **Participants** **(n)** | **Percentage****(%)** |
| --- | --- | --- |
| On foot | 66 | 21.1 |
| By car | 171 | 54.6 |
| Bicycle or Motorcycle | 17 | 5.4 |
| Means of public transportation  | 59 | 18.8 |
| **Total** | **313** | **100.0** |

**Table 11.** Health insurance (public or private)

| **Health insurance** | **Participants** **(n)** | **Percentage (%)** |
| --- | --- | --- |
| Yes | 287 | 91.7 |
| No | 26 | 8.3 |
| **Total** | **313** | **100.0** |

**Table 12.** Actual psychological condition

| **Physical and psychological condition** | **Participants** **(n)** | **Percentage (%)** |
| --- | --- | --- |
| In a peak state | 52 | 16.6 |
| Very good | 102 | 32.6 |
| Good | 99 | 31.6 |
| Mediocre | 49 | 15.7 |
| Bad | 11 | 3.5 |
| **Total** | **313** | **100.0** |

**Table 13.** Participants having previously participated in a clinical trial

| **Previously participated** | **Participants** **(n)** | **Percentage (%)** |
| --- | --- | --- |
|  Yes | 19 | 6.1 |
| No | 294 | 93.9 |
| **Total** | **313** | **100.0** |

**Table 14.** Benefits from participating in medical research or clinical trial

| **Benefits** | **Participants** **(n)** | **Percentage****(%)** |
| --- | --- | --- |
| Clearly Yes | 5 | 26.3 |
| Rather Yes | 12 | 63.2 |
|  Rather No | 1 | 5.3 |
| Clearly No | 1 | 5.3 |
| **Total** | **19** | **100.0** |

**Table 15.** Being under medical treatment for a disease

| **Disease** | **Participants** **(n)** | **Percentage****(%)** |
| --- | --- | --- |
| None | 193 | 61.7 |
| Anxiety | 50 | 16.0 |
| Hypertension | 37 | 11.8 |
| Prehypertension | 34 | 10.9 |
| Depression | 23 | 7.3 |
| Panic attack | 23 | 7.3 |
| Heart diseases | 14 | 4.5 |
| Diabetes Mellitus | 12 | 3.8 |
| Stroke | 2 | 0.6 |
| Psychosis | 1 | 0.3 |
| Unipolar / Bipolar disorder  | 1 | 0.3 |

**Table 16.** Participant information and involvement in the procedure of a clinical trial

|  | **Strongly agree** | **Slightly agree** | **Slightly disagree** | **Strongly disagree** |
| --- | --- | --- | --- | --- |
| The participant receives clear information | 65.8 | 29.7 | 3.8 | 0.6 |
| The participant is offered the opportunity to ask questions | 79.9 | 17.9 | 1.6 | 0.6 |
| The participant is offered the opportunity to voice his or her concerns and views | 63.9 | 27.2 | 6.7 | 2.2 |
| The participant is offered the opportunity to take part in discussions about his or her treatment and care | 65.2 | 29.4 | 4.5 | 1.0 |
| The participant is offered the opportunity to get involved in decision making processes regarding their own treatment and care  | 53.0 | 32.6 | 10.9 | 3.5 |

**Table 17.** Patients’ views on the treatment provided in a clinical trial (%)

|  | **Very significant** | **Fairly significant** | **Slightly significant** | **Insignificant** |
| --- | --- | --- | --- | --- |
| The risks of taking part in a clinical trial | 87.5 | 10.5 | 1.9 | 0.0 |
| The possible side effects of a clinical trial | 86.3 | 12.1 | 1.3 | 0.3 |
| The type of treatment provided | 83.7 | 14.4 | 1.9 | 0.0 |
| Participants’ quality of life might be improved | 81.5 | 16.3 | 1.6 | 0.6 |
| The aim of the treatment provided | 78.6 | 20.1 | 1.3 | 0.0 |
| Possible discomfort, inconvenience or pain related to the participation in a clinical trial | 78.0 | 17.3 | 4.2 | 0.6 |
| Possible benefits that participants may receive from their participation | 77.0 | 19.2 | 2.6 | 1.3 |
| The treatment will be provided free of charge  | 62.6 | 31.0 | 4.8 | 1.6 |

**Table 18.** Participants’ Information provided and expectations related to participation in clinical trials (%)

|  | **Very significant** | **Fairly significant**  | **Slightly****significant** | **Insignificant** |
| --- | --- | --- | --- | --- |
| The clinical trial will be part of a broader medical research study | 62.3 | 34.8 | 1.9 | 1.0 |
| Understanding the purpose of the clinical trial | 66.8 | 30.0 | 2.9 | 0.3 |
| Understanding how the clinical trial might help you at the moment | 67.7 | 27.8 | 4.5 | 0.0 |
| Understanding how the clinical trial might help other patients at the moment | 68.4 | 28.8 | 2.6 | 0.3 |
| Understanding how the clinical trial might help you in the future | 66.1 | 30.4 | 3.5 | 0.0 |
| Understanding how the clinical trial might help other patients in the future | 67.1 | 30.4 | 2.2 | 0.3 |

**Table 19.** Participants’ Information provided and expectations related to convenience and cost / remuneration (%)

|  | **Very significant** | **Fairly significant**  | **Slightly significant** | **Insignificant** |
| --- | --- | --- | --- | --- |
| Possible remuneration for your participation in the clinical trial | 53.4 | 35.8 | 9.6 | 1.3 |
| Eventual additional expenses related to your participation in the clinical trial | 61.0 | 33.9 | 4.8 | 0.3 |
| Convenience of your transportation to a research site | 55.0 | 38.7 | 5.1 | 1.3 |
| Eventual need for you to travel because of your participation in a clinical trial | 52.7 | 34.8 | 10.2 | 2.2 |
| Assistance received by another person in order to facilitate your participation in a clinical trial  | 55.3 | 31.9 | 11.2 | 1.6 |
| Confidentiality of your personal data and results of the study | 68.7 | 25.2 | 5.1 | 1.0 |

**Table 20.** Participants’ Information provided and expectations related to ethics and convenience of participation in the survey (%)

|  | **Very significant**  | **Fairly significant** | **Slightly significant**  | **Insignificant** |
| --- | --- | --- | --- | --- |
| The clinical trial is ethically approved and is under the control of the National Drug Organization | 79.6 | 17.6 | 2.6 | 0.3 |
| The possibility to ask questions to a person tasked with this survey while participating in it | 74.4 | 22.4 | 2.9 | 0.3 |