Supplementary Material

Positive Attitudes and Therapeutic Misconception Around Hypothetical Clinical Trial Participation in the Huntington’s Disease Community

Supplementary Table 1A. Adapted PACT 22 Clinical Trial Attitudes Scale

**Positive Attitudes Subscale** (α = 0.637)

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Statement** | **Category** | **Mean** | **SD** | **SEM** | **Confidence Interval** |
| **Lower** | **Upper** |
| New and better treatments can only be produced if patients agree to take part in clinical trials | Diagnosed with HD | 4.25 | 0.79 | 0.18 | 3.88 | 4.62 |
| Gene Positive | 4.36 | 0.66 | 0.14 | 4.07 | 4.66 |
| Primary Caregiver | 4.55 | 0.57 | 0.10 | 4.34 | 4.76 |
| Total | 4.41 | 0.66 | 0.08 | 4.26 | 4.57 |
| Without the results from clinical trials, doctors would be less able to select the best treatment. | Diagnosed with HD | 4.40 | 0.50 | 0.11 | 4.16 | 4.64 |
| Gene Positive | 4.36 | 0.73 | 0.15 | 4.04 | 4.69 |
| Primary Caregiver | 4.29 | 0.82 | 0.15 | 3.99 | 4.59 |
| Total | 4.34 | 0.71 | 0.08 | 4.18 | 4.51 |
| Pharmaceutical companies should ensure that valid clinical trials are conducted on every drug before it is generally available. | Diagnosed with HD | 4.20 | 0.77 | 0.17 | 3.84 | 4.56 |
| Gene Positive | 4.23 | 1.02 | 0.22 | 3.77 | 4.68 |
| Primary Caregiver | 4.19 | 0.91 | 0.16 | 3.86 | 4.53 |
| Total | 4.21 | 0.90 | 0.10 | 4.00 | 4.41 |
|  If most patients refused to take part in clinical trials, important developments in medicine would be seriously delayed. | Diagnosed with HD | 4.25 | 0.85 | 0.19 | 3.85 | 4.65 |
| Gene Positive | 4.45 | 0.60 | 0.13 | 4.19 | 4.72 |
| Primary Caregiver | 4.35 | 1.11 | 0.20 | 3.95 | 4.76 |
| Total | 4.36 | 0.90 | 0.11 | 4.15 | 4.57 |
|  |  |  |  |  |  |  |

SD, standard deviation; SEM, standard error of the mean

Supplementary Table 1B. Adapted PACT 22 Clinical Trial Attitudes Scale

**Safety Subscale** (α = 0.368)

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| --- | --- | --- | --- | --- | --- |
| **Statement** | **Category** | **Mean** | **SD** | **SEM** | **Confidence Interval** |
| **Lower** | **Upper** |
| Clinical trials are carried out according to strict rules to safeguard the interests of patients. | Diagnosed with HD | 4.30 | 0.98 | 0.22 | 3.84 | 4.76 |
| Gene Positive | 4.32 | 0.78 | 0.17 | 3.97 | 4.66 |
| Primary Caregiver | 4.48 | 0.68 | 0.12 | 4.24 | 4.73 |
| Total | 4.38 | 0.79 | 0.09 | 4.20 | 4.57 |
| I assume that drug treatments that have been prescribed for me (or the person with HD) have already been thoroughly tested in clinical trials. | Diagnosed with HD | 3.85 | 0.59 | 0.13 | 3.58 | 4.12 |
| Gene Positive | 3.41 | 1.30 | 0.28 | 2.83 | 3.98 |
| Primary Caregiver | 3.68 | 1.01 | 0.18 | 3.31 | 4.05 |
| Total | 3.64 | 1.02 | 0.12 | 3.41 | 3.88 |
| Clinical trials are only conducted on drugs for which there is already evidence to show that they are likely to be effective. | Diagnosed with HD | 3.25 | 1.07 | 0.24 | 2.75 | 3.75 |
| Gene Positive | 3.32 | 1.09 | 0.23 | 2.84 | 3.80 |
| Primary Caregiver | 3.23 | 1.09 | 0.20 | 2.83 | 3.62 |
| Total | 3.26 | 1.07 | 0.12 | 3.01 | 3.51 |
| The conduct of all clinical trials is carefully regulated to ensure that the results are valid. | Diagnosed with HD | 4.30 | 0.57 | 0.13 | 4.03 | 4.57 |
| Gene Positive | 4.41 | 0.50 | 0.11 | 4.19 | 4.63 |
| Primary Caregiver | 4.48 | 0.72 | 0.13 | 4.22 | 4.75 |
| Total | 4.41 | 0.62 | 0.07 | 4.27 | 4.56 |
|  |  |  |  |  |  |  |

SD, standard deviation; SEM, standard error of the mean

Supplementary Table 1C. Adapted PACT 22 Clinical Trial Attitudes Scale

**Information Needs Subscale** (α = 0.604)

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| --- | --- | --- | --- | --- | --- |
| **Statement** | **Category** | **Mean** | **SD** | **SEM** | **Confidence Interval** |
| **Lower** | **Upper** |
| I would want as much written information as possible about a clinical trial before I (or the person with HD) agreed to take part. | Diagnosed with HD | 4.05 | 0.83 | 0.18 | 3.66 | 4.44 |
| Gene Positive | 4.41 | 0.59 | 0.13 | 4.15 | 4.67 |
| Primary Caregiver | 4.19 | 0.87 | 0.16 | 3.87 | 4.51 |
| Total | 4.22 | 0.79 | 0.09 | 4.04 | 4.40 |
| I would want to know before agreeing to take part that I (or the person with HD) would be free to withdraw from the clinical trial at any time. | Diagnosed with HD | 3.75 | 0.85 | 0.19 | 3.35 | 4.15 |
| Gene Positive | 4.05 | 0.90 | 0.19 | 3.65 | 4.44 |
| Primary Caregiver | 4.35 | 0.61 | 0.11 | 4.13 | 4.58 |
| Total | 4.10 | 0.80 | 0.09 | 3.91 | 4.28 |
| I would want to know if I (or the person with HD) would be likely to get side effects by taking part in a clinical trial before I agreed to take part. | Diagnosed with HD | 3.90 | 0.85 | 0.19 | 3.50 | 4.30 |
| Gene Positive | 4.18 | 1.01 | 0.21 | 3.74 | 4.63 |
| Primary Caregiver | 4.35 | 0.71 | 0.13 | 4.09 | 4.62 |
| Total | 4.18 | 0.86 | 0.10 | 3.98 | 4.38 |
| I (or the person with HD) would only take part in a clinical trial if I thought I understood everything about it. | Diagnosed with HD | 3.85 | 0.88 | 0.20 | 3.44 | 4.26 |
| Gene Positive | 3.86 | 0.99 | 0.21 | 3.42 | 4.30 |
| Primary Caregiver | 3.94 | 1.03 | 0.19 | 3.56 | 4.31 |
| Total | 3.89 | 0.97 | 0.11 | 3.67 | 4.12 |
|  |  |  |  |  |  |  |

SD, standard deviation; SEM, standard error of the mean

Supplementary Table 1D. Adapted PACT 22 Clinical Trial Attitudes Scale

**Negative Expectations Subscale** (α = 0.732)

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Statement** | **Category** | **Mean** | **SD** | **SEM** | **Confidence Interval** |
| **Lower** | **Upper** |
| I think I would find my (or the person with HD) being in a clinical trial frightening. | Diagnosed with HD | 2.25 | 1.02 | 0.23 | 1.77 | 2.73 |
| Gene Positive | 2.32 | 0.99 | 0.21 | 1.88 | 2.76 |
| Primary Caregiver | 2.19 | 0.91 | 0.16 | 1.86 | 2.53 |
| Total | 2.25 | 0.95 | 0.11 | 2.02 | 2.47 |
| I (or the person with HD) would only take part in the clinical trial if I thought that my own (or their) health would benefit. | Diagnosed with HD | 2.75 | 1.02 | 0.23 | 2.27 | 3.23 |
| Gene Positive | 2.59 | 1.14 | 0.24 | 2.09 | 3.10 |
| Primary Caregiver | 2.26 | 1.12 | 0.20 | 1.85 | 2.67 |
| Total | 2.49 | 1.11 | 0.13 | 2.23 | 2.75 |
| I (or the person with HD) would only take part in a clinical trial if I thought that I would not be inconvenienced by doing so. | Diagnosed with HD | 2.40 | 1.10 | 0.24 | 1.89 | 2.91 |
| Gene Positive | 2.50 | 1.01 | 0.22 | 2.05 | 2.95 |
| Primary Caregiver | 2.16 | 1.00 | 0.18 | 1.79 | 2.53 |
| Total | 2.33 | 1.03 | 0.12 | 2.09 | 2.57 |
| I would only take part in a clinical trial if I knew which treatment I (or the person with HD) was going to receive. | Diagnosed with HD | 2.80 | 1.01 | 0.22 | 2.33 | 3.27 |
| Gene Positive | 2.32 | 0.99 | 0.21 | 1.88 | 2.76 |
| Primary Caregiver | 2.32 | 1.01 | 0.18 | 1.95 | 2.69 |
| Total | 2.45 | 1.01 | 0.12 | 2.22 | 2.69 |
| I (or the person with HD) would only take part in a clinical trial if I was sure that the doctor treating me knew which treatment I (or the person with HD) was getting. | Diagnosed with HD | 3.25 | 1.02 | 0.23 | 2.77 | 3.73 |
| Gene Positive | 2.41 | 1.05 | 0.22 | 1.94 | 2.88 |
| Primary Caregiver | 2.65 | 1.31 | 0.23 | 2.17 | 3.12 |
| Total | 2.74 | 1.19 | 0.14 | 2.46 | 3.02 |
| If I was satisfied with the person with HD’s current drug treatment, I would probably refuse to take a different drug in a clinical trial. | Diagnosed with HD | 2.60 | 0.82 | 0.18 | 2.22 | 2.98 |
| Gene Positive | 2.77 | 0.87 | 0.19 | 2.39 | 3.16 |
| Primary Caregiver | 2.23 | 0.96 | 0.17 | 1.88 | 2.58 |
| Total | 2.49 | 0.91 | 0.11 | 2.28 | 2.71 |
|  |  |  |  |  |  |  |

SD, standard deviation; SEM, standard error of the mean

Supplementary Table 1E. Adapted PACT 22 Clinical Trial Attitudes Scale

**Patient Involvement Subscale** (α = 0.377)

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Statement** | **Category** | **Mean** | **SD** | **SEM** | **Confidence Interval** |
| **Lower** | **Upper** |
| It is important for people with HD to take part in clinical trials to confirm the value of new treatments and / or medical techniques. | Diagnosed with HD | 4.25 | 0.91 | 0.20 | 3.82 | 4.68 |
| Gene Positive | 4.64 | 0.49 | 0.10 | 4.42 | 4.85 |
| Primary Caregiver | 4.65 | 0.49 | 0.09 | 4.47 | 4.82 |
| Total | 4.53 | 0.65 | 0.08 | 4.38 | 4.69 |
| I (or the person with HD) would take part in a clinical trial because the results should benefit HD patients in the future. | Diagnosed with HD | 4.45 | 0.60 | 0.14 | 4.17 | 4.73 |
| Gene Positive | 4.64 | 0.49 | 0.10 | 4.42 | 4.85 |
| Primary Caregiver | 4.55 | 0.57 | 0.10 | 4.34 | 4.76 |
| Total | 4.55 | 0.55 | 0.06 | 4.42 | 4.68 |
| I think all patients who are eligible should be asked to take part in clinical trials. | Diagnosed with HD | 3.30 | 1.34 | 0.30 | 2.67 | 3.93 |
| Gene Positive | 3.91 | 1.19 | 0.25 | 3.38 | 4.44 |
| Primary Caregiver | 4.06 | 1.00 | 0.18 | 3.70 | 4.43 |
| Total | 3.81 | 1.19 | 0.14 | 3.53 | 4.08 |
| Unless advised by their doctor to withdraw from a trial, all patients should cooperate fully until the trial is finished. | Diagnosed with HD | 4.10 | 1.07 | 0.24 | 3.60 | 4.60 |
| Gene Positive | 3.82 | 0.73 | 0.16 | 3.49 | 4.14 |
| Primary Caregiver | 3.61 | 1.23 | 0.22 | 3.16 | 4.06 |
| Total | 3.81 | 1.06 | 0.12 | 3.56 | 4.06 |
|  |  |  |  |  |  |  |

SD, standard deviation; SEM, standard error of the mean

Supplementary Table 2A. Adapted Therapeutic Misunderstanding Scale

**Therapeutic Misconception Subscale** (α = 0.863)

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Statement** | **Category** | **Mean** | **SD** | **SEM** | **Confidence Interval** |
| **Lower** | **Upper** |
| The main reason that people will be recruited for this study is so that they can benefit from the special treatment in this research project. | Diagnosed with HD | 3.40 | 1.39 | 0.31 | 2.75 | 4.05 |
| Gene Positive | 2.32 | 1.09 | 0.23 | 1.84 | 2.80 |
| Primary Caregiver | 2.65 | 1.36 | 0.24 | 2.15 | 3.14 |
| Total | 2.75 | 1.34 | 0.16 | 2.44 | 3.07 |
| The treatment the person with HD would receive in this study will be adapted according to their needs, like the treatment from any other doctor. | Diagnosed with HD | 3.75 | 1.21 | 0.27 | 3.18 | 4.32 |
| Gene Positive | 2.50 | 1.22 | 0.26 | 1.96 | 3.04 |
| Primary Caregiver | 2.87 | 1.36 | 0.24 | 2.37 | 3.37 |
| Total | 3.00 | 1.35 | 0.16 | 2.68 | 3.32 |
| My (or the person with HD's) doctor would adjust the treatment the person with HD receives (e.g., medication dosage) to ensure that they receive the best possible care. | Diagnosed with HD | 4.00 | 0.97 | 0.22 | 3.54 | 4.46 |
| Gene Positive | 2.95 | 1.29 | 0.28 | 2.38 | 3.53 |
| Primary Caregiver | 3.26 | 1.50 | 0.27 | 2.71 | 3.81 |
| Total | 3.37 | 1.36 | 0.16 | 3.05 | 3.69 |
| My (or the person with HD's) doctor would access the information obtained during the course of this clinical trial. | Diagnosed with HD | 3.75 | 1.25 | 0.28 | 3.16 | 4.34 |
| Gene Positive | 2.36 | 1.22 | 0.26 | 1.82 | 2.90 |
| Primary Caregiver | 2.84 | 1.59 | 0.29 | 2.25 | 3.42 |
| Total | 2.95 | 1.48 | 0.17 | 2.60 | 3.29 |
| The treatment that the person with HD would receive may be changed in response to the way their medical condition changes. | Diagnosed with HD | 3.80 | 1.11 | 0.25 | 3.28 | 4.32 |
| Gene Positive | 3.55 | 0.91 | 0.19 | 3.14 | 3.95 |
| Primary Caregiver | 3.23 | 1.26 | 0.23 | 2.76 | 3.69 |
| Total | 3.48 | 1.13 | 0.13 | 3.22 | 3.74 |
| The researchers in this study know that one of the treatments or interventions will have better results than others. | Diagnosed with HD | 3.45 | 1.19 | 0.27 | 2.89 | 4.01 |
| Gene Positive | 2.45 | 1.18 | 0.25 | 1.93 | 2.98 |
| Primary Caregiver | 2.52 | 1.26 | 0.23 | 2.05 | 2.98 |
| Total | 2.75 | 1.28 | 0.15 | 2.46 | 3.05 |
| Medical researchers are only allowed to do things that will benefit all patients. | Diagnosed with HD | 3.25 | 1.12 | 0.25 | 2.73 | 3.77 |
| Gene Positive | 2.41 | 1.10 | 0.23 | 1.92 | 2.90 |
| Primary Caregiver | 2.45 | 1.26 | 0.23 | 1.99 | 2.91 |
| Total | 2.66 | 1.22 | 0.14 | 2.37 | 2.94 |
| The treatment the person with HD would receive is based on their medical needs. | Diagnosed with HD | 3.65 | 1.18 | 0.26 | 3.10 | 4.20 |
| Gene Positive | 2.95 | 1.17 | 0.25 | 2.43 | 3.48 |
| Primary Caregiver | 2.87 | 1.45 | 0.26 | 2.34 | 3.40 |
| Total | 3.11 | 1.33 | 0.16 | 2.80 | 3.42 |
| This clinical trial is conducted mostly to gather knowledge about HD.\* | Diagnosed with HD | 4.05 | 0.94 | 0.21 | 3.61 | 4.49 |
| Gene Positive | 3.91 | 0.75 | 0.16 | 3.58 | 4.24 |
| Primary Caregiver | 4.29 | 0.69 | 0.12 | 4.04 | 4.54 |
| Total | 4.11 | 0.79 | 0.09 | 3.92 | 4.29 |
|  |  |  |  |  |  |  |

*\*The reverse scores were used in analysis*

SD, standard deviation; SEM, standard error of the mean

Supplementary Table 2B. Adapted Therapeutic Misunderstanding Scale

**Therapeutic Misestimation Subscale** (α = 0.870)

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Statement** | **Category** | **Mean** | **SD** | **SEM** | **Confidence Interval** |
| **Lower** | **Upper** |
| The treatment the person with HD would receive in this clinical trial would cure their illness. | Diagnosed with HD | 2.75 | 1.21 | 0.27 | 2.18 | 3.32 |
| Gene Positive | 1.77 | 0.87 | 0.19 | 1.39 | 2.16 |
| Primary Caregiver | 2.16 | 1.13 | 0.20 | 1.75 | 2.58 |
| Total | 2.21 | 1.13 | 0.13 | 1.94 | 2.47 |
| Participation in this clinical trial will prolong the life of the person with HD | Diagnosed with HD | 2.90 | 1.07 | 0.24 | 2.40 | 3.40 |
| Gene Positive | 2.68 | 1.09 | 0.23 | 2.20 | 3.16 |
| Primary Caregiver | 2.71 | 1.24 | 0.22 | 2.25 | 3.17 |
| Total | 2.75 | 1.14 | 0.13 | 2.49 | 3.02 |
| Participation in this study will improve the quality of life of the person with HD. | Diagnosed with HD | 3.60 | 1.05 | 0.23 | 3.11 | 4.09 |
| Gene Positive | 3.32 | 0.95 | 0.20 | 2.90 | 3.74 |
| Primary Caregiver | 3.26 | 1.12 | 0.20 | 2.85 | 3.67 |
| Total | 3.37 | 1.05 | 0.12 | 3.13 | 3.61 |
| Taking part in this research study would cure this person's HD. | Diagnosed with HD | 2.55 | 1.32 | 0.29 | 1.93 | 3.17 |
| Gene Positive | 1.82 | 0.80 | 0.17 | 1.47 | 2.17 |
| Primary Caregiver | 2.10 | 1.14 | 0.20 | 1.68 | 2.51 |
| Total | 2.14 | 1.12 | 0.13 | 1.88 | 2.40 |
| Participation in this clinical trial would boost the immune system of the person with HD. | Diagnosed with HD | 2.95 | 1.15 | 0.26 | 2.41 | 3.49 |
| Gene Positive | 2.27 | 0.83 | 0.18 | 1.91 | 2.64 |
| Primary Caregiver | 2.55 | 1.03 | 0.18 | 2.17 | 2.93 |
| Total | 2.58 | 1.03 | 0.12 | 2.34 | 2.81 |
| I (or the person with HD) am more likely to benefit than the average person. | Diagnosed with HD | 3.45 | 1.05 | 0.23 | 2.96 | 3.94 |
| Gene Positive | 2.95 | 0.90 | 0.19 | 2.56 | 3.35 |
| Primary Caregiver | 3.06 | 1.26 | 0.23 | 2.60 | 3.53 |
| Total | 3.14 | 1.11 | 0.13 | 2.88 | 3.40 |
|  |  |  |  |  |  |  |

SD, standard deviation; SEM, standard error of the mean

Supplementary Table 2C. Adapted Therapeutic Misunderstanding Scale

**Therapeutic Optimism Subscale** (α = 0.788)

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Statement** | **Category** | **Mean** | **SD** | **SEM** | **Confidence Interval** |
| **Lower** | **Upper** |
| I am very optimistic about my (or the person with HD’s) chances for successful treatment. | Diagnosed with HD | 3.45 | 1.23 | 0.28 | 2.87 | 4.03 |
| Gene Positive | 3.00 | 1.07 | 0.23 | 2.53 | 3.47 |
| Primary Caregiver | 3.19 | 1.25 | 0.22 | 2.74 | 3.65 |
| Total | 3.21 | 1.19 | 0.14 | 2.93 | 3.48 |
| There are many ways my participation in this study would help me (or the person with HD). | Diagnosed with HD | 3.90 | 0.79 | 0.18 | 3.53 | 4.27 |
| Gene Positive | 3.64 | 0.90 | 0.19 | 3.24 | 4.04 |
| Primary Caregiver | 3.90 | 1.04 | 0.19 | 3.52 | 4.29 |
| Total | 3.82 | 0.93 | 0.11 | 3.60 | 4.04 |
| My past medical experiences have prepared me well for participation in this study. | Diagnosed with HD | 4.15 | 0.88 | 0.20 | 3.74 | 4.56 |
| Gene Positive | 3.14 | 1.13 | 0.24 | 2.64 | 3.64 |
| Primary Caregiver | 3.52 | 1.09 | 0.20 | 3.12 | 3.92 |
| Total | 3.58 | 1.10 | 0.13 | 3.32 | 3.83 |
| I look forward to participating in this study with hope and enthusiasm. | Diagnosed with HD | 4.20 | 0.83 | 0.19 | 3.81 | 4.59 |
| Gene Positive | 4.18 | 0.73 | 0.16 | 3.86 | 4.51 |
| Primary Caregiver | 4.13 | 0.88 | 0.16 | 3.80 | 4.45 |
| Total | 4.16 | 0.82 | 0.10 | 3.97 | 4.35 |
| I (or the person with HD) look forward to being in this study. | Diagnosed with HD | 4.35 | 0.67 | 0.15 | 4.04 | 4.66 |
| Gene Positive | 3.91 | 0.61 | 0.13 | 3.64 | 4.18 |
| Primary Caregiver | 4.03 | 0.87 | 0.16 | 3.71 | 4.35 |
| Total | 4.08 | 0.76 | 0.09 | 3.91 | 4.26 |
|  |  |  |  |  |  |  |

SD, standard deviation; SEM, standard error of the mean