**Appendix**

**Pre- Post-Assessment for PGG Summit: Results (N=12)**

|  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| PCORI  Engagement Principles | | Items | Pre-test  Mean | | Post-test Mean | | Change | |  |
| CL, TP, TS | | Q1: Identifying and developing research questions to study musculoskeletal conditions including RA, psoriatic arthritis (PsA) and spondyloarthritis (SpA) is important to me. | 5.00 | | 5.00 | | 0.00 | |  |
| CL, TP HN, TS | | Q2: Helping decide the essential characteristics of study participants—like who should be included in a study of musculoskeletal conditions—is important to me. | 4.50 | | 4.33 | | -0.17 | |  |
| CL, TP, HN, TS | | Q3: If an intervention for musculoskeletal conditions is being studied, I would like to help create the intervention and identify the comparison or control group. | 4.25 | | 4.42 | | 0.17 | |  |
| TP | | Q4: It is easy for me to find opportunities to participate in arthritis research as a study participant. | 3.42 | | 3.75 | | 0.33 | |  |
| CL, TP, HN, TS | | Q5: It is best for research when patient partners participate in and monitor how a study is conducted. | 3.25 | | 3.25 | | 0.00 | |  |
| RR, CL | | Q6: I understand my role as a Patient Governor with ArthritisPower. | 4.25 | | 5.80 | | 1.55 | |  |
| RR, CL, TP, HN | | Q7: I am willing to help disseminate research results from ArthritisPower to other patients and other audiences so that the findings are communicated in understandable, usable ways. | 4.92 | | 5.00 | | 0.08 | |  |
| RR, CL | | Q8: My role and decision-making authority as a Patient Governor is clear to me. | 4.25 | | 4.83 | | 0.58 | |  |
| PA | | Q9: I am being fairly compensated for my time and contribution as a Patient Governor. | 5.17 | | 4.92 | | -0.25 | |  |
| PA | | Q10: I trust that my unique characteristics, including cultural diversity and/or disability, will be accommodated by GHLF/CreakyJoints during my involvement as a Patient Governor. | 5.00 | | 5.08 | | 0.08 | |  |
| CL, TP, HN, TS | | Q11: Major decisions about ArthritisPower are being made inclusively. | 4.09 | | 4.92 | | 0.83 | |  |
| TP, HN, TS | | Q12: Information about ArthritisPower is being shared readily with Patient Governors. | 4.64 | | 4.92 | | 0.28 | |  |
|  |  |  |  |  |  |  |  |  |  |

Each item was rated from 1=Strongly Disagree to 6=Strongly Agree.

RR = Reciprocal Relationships

CL = Co-Learning

PA = Partnership

TP = Transparency

HN = Honesty

TS = Trust

**Patient-Led Mid-Year Evaluation: Interview Prompts and Probes**

Please rate on a scale of 1 to 10, with 1 being “Terrible” and 10 being “Great” the following factors:

1. How are you feeling about the progress of Arthritis Power toward conducting patient-centered research in rheumatology?

* Probe: Please tell me the reasons you gave this rating.
* Probe: What do you think would speed the progress of ArthritisPower Power toward conducting patient-centered research in rheumatology?

2. How are you feeling about your participation on the Patient Governor Group?

* Probe: What would help improve your engagement with the Patient Governor Group?

3. How are you feeling about the support you receive from CreakyJoints staff as a Patient Governor?

* Probe: What do you like about the support you receive from staff?
* Probe: What would improve the support you receive from staff?

4. How are you feeling about the support you receive from other Patient Governors?

* Probe: What do you like about the support you receive from other PGs?
* Probe: What would improve the support you receive from other PGs?