Roles and Skills for Patient Partners in Research

As a patient partner on a health research team, you may ask yourself, ‘What can I contribute’? The answer is, more than you may think! We all bring transferable skills to the table that are usually broader than any given role within a team. They relate more to leadership, communication, critical thinking, analysis, and organizational abilities, strengths and experiences. These are skills that can be transferred and utilized in a variety of different ways as a patient partner.

- Facilitating meetings or discussions
- Leading activities
- Setting goals and priorities
- Manage people, delegate tasks, direct, oversee or motivate
- Note taking
- Learning by listening
- Solving problems in a cooperative way
- Business writing
- Editing documents/reports
- Sharing personal stories in a public venue
- Sharing personal stories through written communication
- Teaching, training, or mentoring
- Interviewing others
- Event planning
- Researching information
- Graphic design
- Web design
- Sharing and promoting on social media
- Creative Thinking
- Interpersonal Skills
<table>
<thead>
<tr>
<th>Role for Patient Partner</th>
<th>Complimentary Skills</th>
<th>I have experience</th>
<th>I am interested</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Research Process, Step 1: Identifying and Prioritizing Research Question</strong></td>
<td></td>
<td>yes</td>
<td>no</td>
</tr>
<tr>
<td>1. Consult on research topics and collaborate to develop priorities</td>
<td>✔ Participating in group discussions ✔ Active listening ✔ Setting goals and priorities ✔ Creative thinking ✔ Researching information</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Research Process, Step 2: Study Design</strong></td>
<td></td>
<td>yes</td>
<td>no</td>
</tr>
<tr>
<td>1. Inform study design, clarify the research question and affirm its importance</td>
<td>✔ Participating in group discussions ✔ Setting goals and priorities</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Ensure the methods selected are appropriate for patients</td>
<td>✔ Participating in group discussions ✔ Learning by listening</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Co-develop patient recruitment strategy</td>
<td>✔ Interviewing others ✔ Sharing and promoting materials ✔ Teaching, training, or mentoring</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Review and comment on proposed questionnaires and data collection methods</td>
<td>✔ Business writing ✔ Editing documents/reports</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Research Process, Step 3: Development of Grant Proposal to Fund Project</strong></td>
<td></td>
<td>yes</td>
<td>no</td>
</tr>
<tr>
<td>1. Ensure the research and methods proposed are ethical</td>
<td>✔ Learning by listening ✔ Participating in group discussions ✔ Researching information</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Identify areas where patients and the public could be involved</td>
<td>✔ Managing people and delegating tasks ✔ Creative thinking</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Define outcome measures</td>
<td>✔ Researching information</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Advise on the appropriateness of the lay summary</td>
<td>✔ Taking notes, editing documents/reports</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Identify costs of involvement, expenses</td>
<td>✔ Participating in group discussions</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Research Process, Step 4: (pre) Study Preparation &amp; Administration</strong></td>
<td></td>
<td>yes</td>
<td>no</td>
</tr>
<tr>
<td>1. Assist with writing patient agreement and consent forms</td>
<td>✔ Communication ✔ Writing, editing documents/reports</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
| 2. | Review ethics and operational approval applications prior to submission | ✓ Communication  
 ✓ Writing, editing documents/reports  
 ✓ Learning by listening |
|---|---|---|
| 3. | Aid in designing the detailed protocol | ✓ Communication  
 ✓ Writing, editing documents/reports |
| 4. | Develop research updates that are patient friendly | ✓ Communication  
 ✓ Writing, editing documents/reports |
| 5. | Become a co-applicant | ✓ Participating in group discussions  
 ✓ Writing, editing documents/reports |

**Research Process, Step 5: Data Collection**

| 1. | Draft and revise study materials and protocols | ✓ Writing, editing business documents/reports  
 ✓ Graphic design |
|---|---|---|
| 2. | Assist with the recruitment of study participants | ✓ Leading meetings, discussions or activities  
 ✓ Teaching, training, or mentoring  
 ✓ Interviewing  
 ✓ Interpersonal Skills |
| 3. | Assist with conducting interviews and surveys | ✓ Leading meetings, discussions or activities  
 ✓ Interviewing  
 ✓ Interpersonal Skills |

**Research Process, Step 6: Analyzing and Interpreting Data**

| 1. | Assist the research team in developing themes from data | ✓ Analyzing and problem solving  
 ✓ Active listening  
 ✓ Creative thinking |
|---|---|---|
| 2. | Consult with research team on interpretation of data | ✓ Analyzing and problem solving  
 ✓ Actively listening  
 ✓ Participating in group discussions  
 ✓ Active listening |
| 3. | Develop more approachable methods to help interpret the data | ✓ Evaluating and solving problems cooperatively |

**Research Process, Step 7: Dissemination of Results (of what to whom?)**

| 1. | Advise on ways to disseminate results | ✓ Teaching, training, or mentoring  
 ✓ Sharing and promoting materials |
|---|---|---|
| 2. | Author/co-author manuscripts, newsletters and other appropriate information outlets | ✓ Writing, editing documents/reports  
 ✓ Communications |
### Skills & Contribution Chart

| 3. Jointly present the findings with researchers | ✓ Leading meetings or discussions  
✓ Teaching, training, or mentoring  
✓ Public Speaking |
| 4. Help distribute results within informal network | ✓ Sharing and promoting materials  
✓ Leading activities |
| 5. Produce summaries of findings | ✓ Graphic design  
✓ Business writing |

#### Research Process, Step 9: Implementation (Knowledge to Action)

| 1. Increase the likelihood that results of research are implemented, by adding validity to the findings | ✓ Setting goals and priorities  
✓ Creative / Strategic thinking |
| 2. Develop patient information for new services/interventions within hospitals, clinics, etc. | ✓ Graphic/web design  
✓ Sharing and promoting materials  
✓ Leading activities |

#### Research Process, Step 10: Monitoring and Evaluation

| 1. Continue involvement with the study to maintain focus and address issues as they arise | ✓ Solving problems cooperatively |
| 2. Collaborate with researchers to evaluate the research process | ✓ Leading meetings or discussions  
✓ Solving problems cooperatively |
| 3. Reflect on roles, responsibilities and lessons learned | ✓ Participating in discussions  
✓ Actively listening |