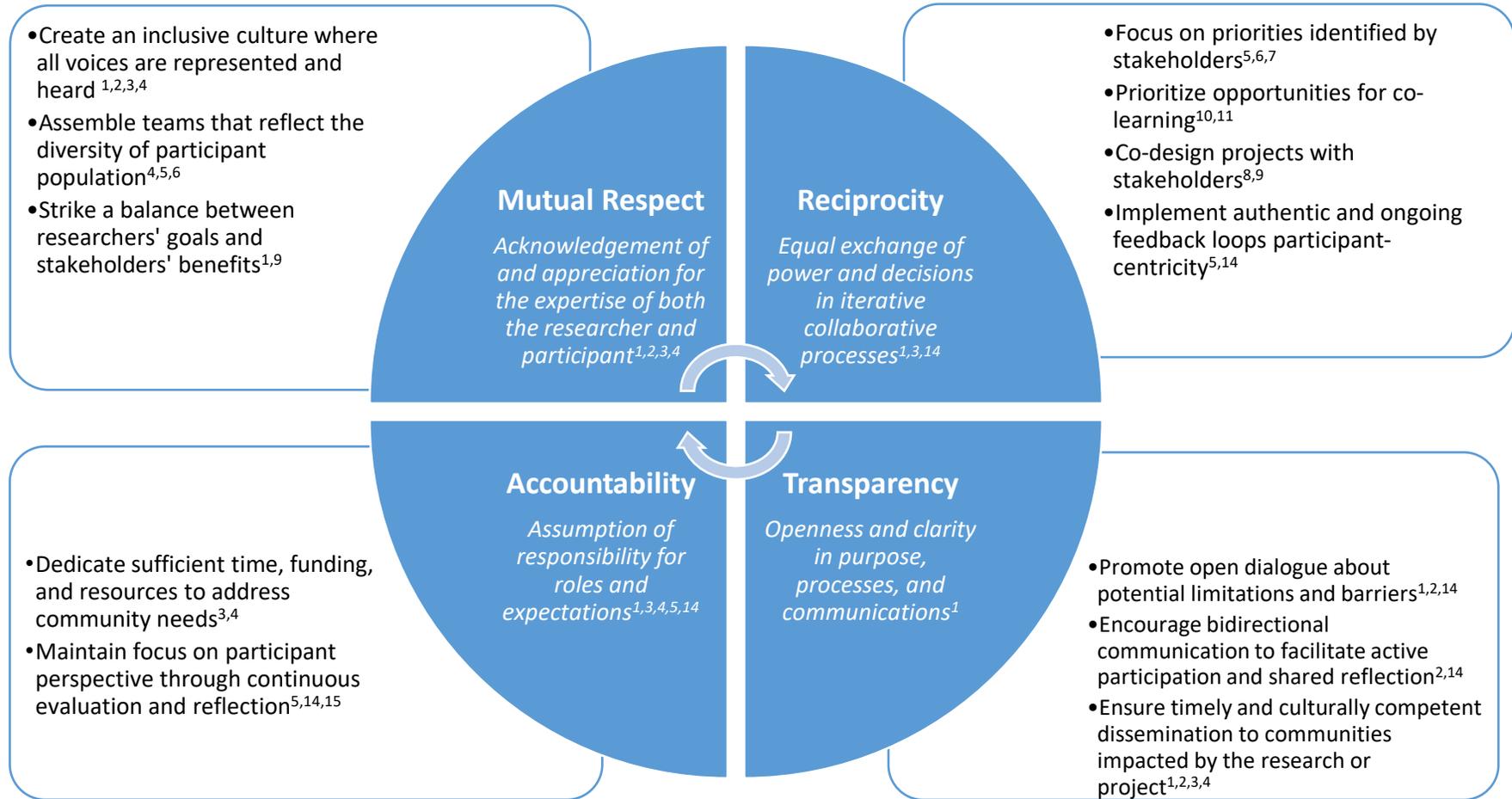




## Guide to People-Centered Community Research Improving the Quality of Participant Leadership



**Note:** “Stakeholder” in this document refers to an individual who is affected by or contributes to study outcomes. This group may include patients, family caregivers, advocates, clinicians, researchers, policy makers, payers, and other groups for whom the results of the research will be relevant.<sup>16</sup> This description is intentionally broad in an effort to be inclusive and engaging for patient participants. There may be subsets of these populations applicable in across various studies.

Key Principle from Cycle	Description	Tactics	Indicators and Tracked Documentation
<b>Research Planning and Proposal Development</b>			
<b>Mutual Respect</b>	<ul style="list-style-type: none"> <li>• Demonstrated willingness to listen to others, particularly with different perspectives</li> <li>• Focus on cultural sensitivity and cultural humility</li> </ul>	<ul style="list-style-type: none"> <li>• Determine which cultural literacy indicators are appropriate and set up dashboard for open and transparent reporting</li> </ul>	<ul style="list-style-type: none"> <li>• Stakeholder Memorandum of Understanding with agreements detailing:               <ul style="list-style-type: none"> <li>○ Commitment to a communication plan and system suited to the preferred methods of stakeholders</li> <li>○ Distribution of common language definition document to stakeholders</li> <li>○ Plans for integration of the definitions into research protocol</li> </ul> </li> <li>• Agreement about the dashboard elements, methods for measurement, and audience</li> </ul>
<b>Transparency</b>	<ul style="list-style-type: none"> <li>• All stakeholders engage in open communication</li> </ul>	<ul style="list-style-type: none"> <li>• Design communication systems native to each stakeholder group</li> <li>• Craft a dictionary of terms</li> </ul>	<ul style="list-style-type: none"> <li>• Stakeholder-reported satisfaction feedback</li> <li>• Agreement on level of literacy</li> <li>• Collaborative document of definitions and commonly used terms</li> </ul>
<b>Project Implementation</b>			
<b>Reciprocity</b>	<ul style="list-style-type: none"> <li>• All stakeholders have decision making authority and opportunities to voice perspectives</li> </ul>	<ul style="list-style-type: none"> <li>• Discuss various partners strengths and weaknesses</li> <li>• Fair and accessible process to resolve inevitable differences in desired outcomes</li> </ul>	<ul style="list-style-type: none"> <li>• Iterative objectives and outcomes process</li> <li>• Measurable objects and outcomes (distributed)</li> <li>• Assessment and agreement of research initiative and protocol infrastructure</li> </ul>
<b>Accountability</b>	<ul style="list-style-type: none"> <li>• Clear understanding of partners' expertise, strengths, and roles</li> <li>• Assessment of the value of various outcomes to the different stakeholders</li> </ul>	<ul style="list-style-type: none"> <li>• Explicit articulation and discussion of roles</li> <li>• Involve stakeholders in creation of measurable objectives and outcomes</li> </ul>	<ul style="list-style-type: none"> <li>• Clarification of anticipated timeline, roles, expectations</li> <li>• Signed project charter, MOU, SOP, and conflict resolution policies</li> <li>• Statement of Work (with time commitment and fair compensation included)</li> <li>• List of needs and benefits for stakeholders</li> <li>• Information about compensation that reflects equanimity across all stakeholders</li> <li>• Annotated minutes from meetings or calls that demonstrate or explain balance/compromise among stakeholders</li> </ul>

## Data Collection

<b>Reciprocity</b>	<ul style="list-style-type: none"> <li>• Support the participation of various stakeholders in the project's phases</li> <li>• Engage stakeholders representing the relevant culture</li> <li>• Analyze results from stakeholder lens</li> </ul>	<ul style="list-style-type: none"> <li>• Allow team members to anonymously share in ongoing forum</li> <li>• Ensure mechanism for receiving input early, and during the relevant phase, so that feedback can be incorporated and shift research plans</li> <li>• Maintain ongoing participation of diverse stakeholders in meetings and activities</li> </ul>	<ul style="list-style-type: none"> <li>• Codeisgned recruitment strategy</li> <li>• Attendance log that tracks attendance and participation</li> <li>• Demonstrated opportunity for pre- and post-meeting follow-ups</li> <li>• Recruitment and retention rates</li> <li>• Revised research and recruitment plans</li> <li>• Participation rate in forum</li> <li>• Percentage of stakeholders who contributed feedback</li> </ul>
<b>Transparency</b>	<ul style="list-style-type: none"> <li>• Value differences of contributing stakeholders (diversity of populations for research question)</li> <li>• Articulate cultural value for the community/study</li> </ul>	<ul style="list-style-type: none"> <li>• Develop research and/or engagement plan featuring evidence of these principles</li> </ul>	<ul style="list-style-type: none"> <li>• Documentation of:             <ol style="list-style-type: none"> <li>1. Study design reflecting diversity of expertise and experience</li> <li>2. Input from diverse sources</li> </ol> </li> <li>• Explanation of team's mastery of cultural sensitivity</li> <li>• Accommodations made for stakeholders who are not available during standard work hours</li> <li>• Meeting minutes distributed and made accessible</li> <li>• Written plan to address turnover of stakeholders</li> </ul>

## Dissemination and Evaluation Reporting

<b>Accountability</b>	<ul style="list-style-type: none"> <li>• Widespread dissemination of findings to all interested, particularly clinicians and patients, in their own language</li> </ul>	<ul style="list-style-type: none"> <li>• Early plan for specifically where, when, and how the dissemination will occur – (prior to the study launch)</li> <li>• Ongoing and post-study evaluation to assess how well these principles were</li> </ul>	<ul style="list-style-type: none"> <li>• Co-developed dissemination plan</li> <li>• Documented feedback incorporated over the course of the study</li> <li>• Public summary of evaluations</li> <li>• Quality improvement and evaluation plan completed</li> </ul>
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		adhered to throughout the process	
<b>Transparency</b>	<ul style="list-style-type: none"> <li>• Translation into accessible formats, including those associated with social media and other current forms of communication (infographics, videos, etc.)</li> </ul>	<ul style="list-style-type: none"> <li>• Translation of findings from scientific and medical language to lay language</li> </ul>	<ul style="list-style-type: none"> <li>• Co-presentation in conferences and working group meetings to discuss findings</li> <li>• Lay document of study results</li> <li>• Publish, blog, and share on social media study updates and findings throughout the project life cycle.</li> <li>• Number of diverse formats and platforms utilized</li> <li>• Analytics for response to tangible products (i.e. hits, downloads, click-through rates, likes, and views)</li> </ul>

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