

## Alliance Principles of Patient Engagement in Research

**Purpose — the engagement of patients in all stages of research significantly increases the impact of improving the health of people with progressive MS**

*People affected by MS have been at the heart of the Alliance since its beginning, including individuals serving on the Scientific Steering Committee, the development of the People Affected by MS Engagement Coordination Team and the ongoing partnership with MULTI-ACT*

Principle	Principle in Action
<p><b>Partnership with Focus</b>                      Patient priorities, engagement and involvement are in force throughout the research continuum, from strategy development to communicating results as equal collaborators</p>	<ul style="list-style-type: none"> <li>• Patient problem resolution is at the forefront of all research discussion and decision-making</li> <li>• Co-design and collaborative decision-making among all stakeholders at all stages, lab-based and clinical</li> <li>• Clarity of roles among all stakeholders defined</li> <li>• Communication of all research and clinical trial results</li> <li>• Processes and results are transparent and accessible</li> <li>• Patients serve as co-authors in scientific paper development and publication</li> <li>• Ongoing monitoring and evaluation of the patient engagement process conducted</li> </ul>
<p><b>Mutual Respect</b>                      All stakeholders including patients, scientists, healthcare professionals, industry experts, MS organization leaders and people affected by MS are acknowledged, valued and engaged as essential contributors to the research process</p>	<ul style="list-style-type: none"> <li>• The experiential knowledge of patients is valued and acknowledged as part of the research process</li> <li>• Patients’ perspectives and lived experiences are sought, heard, understood and incorporated in discussions and decision-making</li> <li>• Expectations provided for all stakeholders so that they can work and communicate meaningfully and effectively</li> <li>• All stakeholders are empowered to provide their perspective and have them thoughtfully considered</li> <li>• Trust among stakeholders instills confidence of the honesty, fairness, and reliability of the research process</li> </ul>
<p><b>Inclusivity</b>                      A diverse range of lived experiences by patients is actively sought and included throughout the research process</p>	<ul style="list-style-type: none"> <li>• Concerted efforts made to include representative populations of patients in clinical research wherever possible including considerations of age, gender, ethnicity, geography, disease state, and socio-economic condition</li> <li>• Plain language used throughout the research process to ensure active participation by patients</li> <li>• Experiential knowledge valued as evidence in the research process</li> <li>• Patient reported outcomes developed, validated and accepted as part of the research and clinical trial process</li> <li>• No barriers exist to full patient participation</li> </ul>
<p><b>Access, Accommodation and Support</b>                      Adequate time, support and flexibility are provided to patient participants to ensure they can participate in all aspects along the research continuum</p>	<ul style="list-style-type: none"> <li>• A plan of support including travel, accommodations, technology and scheduling provided</li> <li>• Emotional and social support available</li> <li>• Financial means is not a barrier to participation</li> <li>• A safe and open environment is provided</li> <li>• Language should not be a barrier</li> <li>• Training is provided for all stakeholders</li> </ul>