

Supplementary table 5 Stakeholders and participants at centres RZM and MUW during Visits 1-8, focus groups, and interviews

Event and Assessments	Stakeholders	Participants	Findings and Learnings
<p><b>V1: Kick-off meeting with stakeholders</b></p> <p><b>Purpose</b></p> <ul style="list-style-type: none"><li>Getting to know each other and building up a relationship</li><li>Communication strategies within a PPI project</li><li>Presentation of project objectives and benefits</li><li>Explanation of the project plan</li><li>Roles, responsibilities, and accountabilities</li><li>Assignment of roles</li><li>Feedback session, questionnaire, and evaluation</li></ul> <p><b>Method</b></p> <p>Hybrid-meeting (online and in-person) at the two study sites, direct presentation</p> <p><b>Assessments</b></p> <ul style="list-style-type: none"><li>PC including SD</li><li>USE-MS-G</li><li>SAM</li></ul>	<p>RZM: 1-11</p> <p>MUW: 12-18</p>	<p>-</p>	<p><b>Findings</b></p> <ul style="list-style-type: none"><li>Stakeholders expressed interest in receiving layperson-friendly information to better understand the study processes.</li></ul> <p><b>Learnings</b></p> <ul style="list-style-type: none"><li>Stakeholders wished to make their voices heard</li><li>Stakeholders who are musicians, dancers, or music- or physiotherapists volunteered.</li><li>Networking with new contacts and the provision of additional information on project design were positively acknowledged.</li></ul>
<p><b>V2: Co-creative Workshop 1</b> on qualitative research methods</p> <p><b>Purpose</b></p> <p>To inform about basic principles of qualitative research methods and refine interview guidelines for semi-structured interviews and focus groups.</p>	<p>RZM: 1-2, 6-10</p> <p>MUW: 12-15, 17-18, 52, 58-59</p>	<p>-</p>	<p><b>Findings</b></p> <p>With ongoing support, initial questions for the interview guidelines were collaboratively formulated:</p> <ul style="list-style-type: none"><li>Information regarding technical requirements should be gathered.</li><li>Preferences for individual versus group training could also be assessed.</li></ul>

<p><b>Method</b> In-person, group discussion, lecture</p> <p><b>Assessments</b></p> <ul style="list-style-type: none"><li>• PC including SD</li><li>• USE-MS-G</li><li>• SAM</li></ul>			<ul style="list-style-type: none"><li>• Data should be collected about the duration and timing of training sessions, as well as the type of exercise.</li></ul> <p><b>Learnings</b></p> <ul style="list-style-type: none"><li>• Participants appreciated the relaxed atmosphere of the meeting.</li><li>• Some participants required several attempts to fully understand the concept of qualitative research. A follow-up one-on-one meeting was proposed.</li><li>• More details on the assigned roles were requested.</li></ul>
<p><b>Visit 3: Co-Creative Workshop 2</b> on data collection and analysis</p> <p><b>Purpose</b> To discuss the methodology of data collection and analysis in qualitative research, with an emphasis on co-analysis opportunities and the consideration of relevant aspects.</p> <p><b>Method</b> In-person, group discussion, lecture</p> <p><b>Assessments</b></p> <ul style="list-style-type: none"><li>• PC including SD</li><li>• USE-MS-G</li><li>• SAM</li></ul>	<p>RZM: 1-2, 6</p> <p>MUW: 12-13, 17-18, 52, 58-59</p>	-	<p><b>Findings</b></p> <ul style="list-style-type: none"><li>• Stakeholders were particularly engaged in learning about thematic analysis in qualitative research methods and pointed out relevant statements for the further development of the exercise intervention.</li><li>• Stakeholders appreciated detailed explanations regarding how their personal data, as well as that of other participants, would be anonymised, pseudonymised, and securely stored.</li><li>• Furthermore, stakeholders were interested in knowing the specific time points and frequency of data collection throughout the study.</li></ul> <p><b>Learnings</b></p> <ul style="list-style-type: none"><li>• Stakeholders reported feeling highly involved.</li><li>• Researchers learned more about personal preferences and adopting their language to the needs of pwMS.</li></ul>
<p><b>Focus groups and interviews Stage 1</b></p> <p><b>Purpose</b></p>	<p>RZM: 1-2, 4, 7, 9</p>	<p>RZM: 21-40</p>	<p><b>Findings</b></p>

<p>To gather insights for the basis of developing a music-supported exercise programme for pwMS.</p> <p><b>Topics</b></p> <ul style="list-style-type: none"><li>• Exercising with multiple sclerosis</li><li>• Exercise location, time and duration</li><li>• Music preferences</li><li>• Video-based exercise programmes</li><li>• Structure of music-supported videos</li></ul> <p><b>Method</b></p> <p>RZM: 3 focus groups, 10 interviews</p> <p>MUW: 2 focus groups, 9 interviews</p>	MUW: 18	MUW: 19-20, 50-51, 53-57, 60-65	<ul style="list-style-type: none"><li>• Three levels of difficulty in various positions (sitting, standing, lying) were desired for each exercise for pwMS with various degrees of physical fitness.</li><li>• The programme should include exercises specifically for wheelchair users.</li><li>• A duration of 1-3 minutes per exercise was suggested by pwMS.</li><li>• There were substantial differences between stakeholders and participants with MS with respect to music genre preferences.</li><li>• Music enhances participants' motivation to engage in exercise programmes, especially when done at home. There was a clear desire for personalised, music-supported home workout routines.</li><li>• Participants wanted a variety of musical styles, with a strong preference for well-known songs and 'oldies' from the 1950s to the 1980s.</li><li>• All pwMS strongly desired to create their individual music-supported exercise programme from a database or using a software application</li><li>• Music was suggested both as a rhythm provider and for background e. g., with strength training or stretching.</li><li>• Five exercise categories emerged from the process, with respect to practicing: balance, strength &amp; endurance, fine motor skills, flexibility, relaxation &amp; breathing, and dance including and mobility.</li></ul> <p><b>Learnings</b></p>
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			<ul style="list-style-type: none"><li>Participants expressed appreciation for the opportunity to discuss their personal exercise routines with others, exchanging ideas on potential exercise regimens and available spaces for physical activity.</li><li>Additionally, participants noted the relaxed and welcoming atmosphere of the workshop and the provision of refreshments and snacks.</li></ul>
<p><b>Visit 4: Co-creation Workshop 3</b> on exercise development</p> <p><b>Purpose</b> To identify exercises for an effectively combination with music-rhythmic cues, offering participants the opportunity to try different exercises with varying forms of auditory support.</p> <p><b>Method</b> In-person, group discussion</p> <p><b>Assessments</b></p> <ul style="list-style-type: none"><li>PC including SD</li><li>USE-MS-G</li><li>SAM</li></ul>	<p>RZM: 1-2, 4, 6-7, 10-11</p> <p>MUW: 12-18, 52, 58-59</p>	-	<p><b>Findings</b></p> <ul style="list-style-type: none"><li>A broad range of motor activities was suggested to address mild to severe disability levels due to MS.</li><li>Every statement and opinion were taken very seriously throughout the study.</li></ul> <p><b>Learnings</b></p> <ul style="list-style-type: none"><li>Stakeholders expressed strong satisfaction with the project, encouraging the continuation of the current approach.</li><li>Overall, stakeholders appreciated the project.</li></ul>
<p><b>Visit 5: Music co-selection meeting</b></p> <p><b>Purpose</b> To select appropriate music for use in exercise programmes for pwMS, focusing on the therapeutic potential of rhythm, melody, and genre preferences to promote movement and engagement.</p>	<p>RZM: 1-3, 5, 6-8, 10-11</p> <p>MUW: 12-18, 52, 58-59</p>	-	<p><b>Findings</b></p> <ul style="list-style-type: none"><li>It was considered desirable to include various rhythmic options, offering both slower and faster alternatives.</li><li>A clear, consistent rhythm was noted to enhance concentration during exercises.</li></ul>

<p><b>Method</b> In-person group discussion</p> <p><b>Assessments</b></p> <ul style="list-style-type: none"><li>• PC including SD</li><li>• USE-MS-G</li><li>• SAM</li></ul>			<ul style="list-style-type: none"><li>• The use of a metronome or rhythmic cue was proposed to aid in guiding participants. While this feature could offer benefits, it was also acknowledged that it might create stress for some individuals.</li></ul> <p><b>Learnings</b></p> <ul style="list-style-type: none"><li>• Music was identified as a flexible variable that could function either as a pacemaker or as background accompaniment. However, opinions regarding its effects varied among individuals.</li></ul>
<p><b>Focus groups and interviews Stage 2</b></p> <p><b>Purpose</b> To discuss and evaluate music-supported video samples, which were developed based on insights from the co-workshops and the analysis of the first stage of interviews, to gather feedback and refine the selection.</p> <p><b>Topics</b></p> <ul style="list-style-type: none"><li>• Exercise selection</li><li>• Music selection</li><li>• Exercise content</li><li>• Personalisation and relevance</li></ul> <p><b>Method</b> RZM: 3 focus groups, 6 interviews MUW: 2 focus groups, 4 interviews</p>	<p>RZM: 1-2, 4, 7, 9</p> <p>MUW: 18</p>	<p>RZM: 21-22, 24, 26, 33-37, 40-44</p> <p>MUW: 19-20, 50-51, 53-57, 60-66</p>	<p><b>Findings</b></p> <ul style="list-style-type: none"><li>• PwMS expressed a wish to exercise at home guided by exercise and dance-exercise videos, with exercises presented by casually dressed therapists in a non-clinical environment.</li><li>• Exercise instructions should be informative and motivating, e.g. with a countdown, including effortless ease and humour.</li><li>• Safety instructions and other key aspects should be integrated using short videos</li><li>• Some participants preferred exercise videos conducted in outdoor settings. The setting should be non-clinical.</li><li>• Participants expressed a preference for movement and dance-based exercise videos led by therapists. in casual clothing. The occurrence of minor errors by instructors is deemed acceptable, as it contributes to a relatable and authentic experience for participants.</li></ul>

			<ul style="list-style-type: none"><li>• Most participants appreciated the idea to create their own personalised, music-supported exercise programmes using a database or software application.</li><li>• Every participant reported to have access to a device (PC, smartphone, TV, laptop, or tablet) to perform the exercises.</li><li>• Everyday objects were preferred over conventional therapy material or devices e.g., water bottles instead of dumbbells</li></ul> <p><b>Learnings</b></p> <ul style="list-style-type: none"><li>• Smaller focus groups had to be formed due to some cancellations.</li><li>• Additionally, some participants expressed that the hospital environment was not conducive to participating in interviews.</li><li>• Participants acknowledged the vouchers provided as compensation for their time, which was appreciated.</li></ul>
<p><b>Visit 6: Co-Creative Workshop 4</b> on findings co-dissemination (article co-writing, poster co-writing and co-presentation)</p> <p><b>Purpose</b> To facilitate a collaborative exchange where stakeholders gain insights into scientific writing, article structure, and the writing process, while also discussing how researchers can learn from their experiences and perspectives to enhance the quality and relevance of scientific outputs e.g. scientific posters.</p>	<p>RZM: 1-2, 6-10</p> <p>MUW: 12-18, 52, 58</p>	-	<p><b>Findings</b></p> <ul style="list-style-type: none"><li>• Articles for patient magazines were written by stakeholders to share their perspectives on the project.</li><li>• Two posters were co-created and co-presented at conferences.</li></ul> <p><b>Learnings</b></p> <ul style="list-style-type: none"><li>• Some stakeholders actively contributed to the presentation of results and had the opportunity to</li></ul>

<b>Assessments</b> <ul style="list-style-type: none"><li>• PC including SD</li><li>• USE-MS-G</li><li>• SAM</li></ul>			exchange perspectives with other attendees and researchers from different fields at conferences.
<b>Visit 7: Final video recording</b>  <b>Purpose</b> To capture a selection of exercises in three difficulty levels and varying positions, covering five categories: balance and coordination, strength and endurance, fine motor skills, flexibility, relaxation and breathing, and dance, including mobility, following the analysis of stage 2.  <b>Method</b> A professional video company recorded music-supported exercises and expert interviews conducted by stakeholders.  <b>Assessments</b> <ul style="list-style-type: none"><li>• PC including SD</li><li>• USE-MS-G</li><li>• SAM</li></ul>	RZM: 1-2, 7  MUW: 18, 58	-	<b>Findings</b> <ul style="list-style-type: none"><li>• The stakeholders served in the capacity of interviewers for both the informational videos and the dance component of the training programme.</li></ul> <b>Learnings</b> <ul style="list-style-type: none"><li>• The collaboration between stakeholders and researchers was considered highly valuable.</li><li>• By supporting each other throughout the process, stakeholders found the experience both enjoyable and rewarding.</li><li>• A supportive, collaborative environment enhances the overall experience and engagement of all participants, making complex tasks more manageable and enjoyable.</li></ul>
<b>Focus groups and interviews Stage 3</b>  <b>Purpose</b> To gather general feedback on the initial exercise videos, including their music elements, structure, and overall impression, in order to refine the videos for final use.  <b>Topics</b>	RZM: 1-2, 4, 7, 9, 18  MUW: 18	RZM: 21, 24, 26, 32-34, 38-40, 42-49	<b>Findings</b> <ul style="list-style-type: none"><li>• The accessibility of the videos could be improved for pwMS with visual or hearing impairments.</li><li>• Family members supported the overall process and provided feedback and guidance for the research team.</li></ul> <b>Learnings</b>

<ul style="list-style-type: none"><li>• General feedback on final videos</li><li>• Music elements</li><li>• Instruction videos</li><li>• Structure and overall impression</li></ul> <p><b>Method</b> RZM: 1 focus group, 6 interviews MUW: 1 focus group, 3 interview</p>		MUW: 51, 55-57, 60-62, 65-70	<ul style="list-style-type: none"><li>• The Stakeholders had a significant impact on the outcomes of this project.</li><li>• The Stakeholders reported feeling highly involved.</li><li>• As experts in lived experience, the Stakeholders challenged the traditional views of the researchers and developed new ideas.</li></ul>
<p><b>Visit 8: Closing Event</b></p> <p><b>Purpose</b> To actively involve the stakeholders in the dissemination process, aiming to present their work and engage in the MS community.</p> <p><b>Assessments</b></p> <ul style="list-style-type: none"><li>• PC including SD</li><li>• USE-MS-G</li><li>• SAM</li><li>• PAS</li></ul>	RZM: 1-11  MUW: 12-18, 52, 58	RZM: 24, 26-28, 33, 37, 40-42, 44, 48  MUW: 51, 55, 56, 60	<p><b>Findings</b></p> <ul style="list-style-type: none"><li>• The music-supported video programme was presented as part of World MS Day in Tirol and at a separately organised event in Vienna.</li></ul> <p><b>Learnings</b></p> <ul style="list-style-type: none"><li>• Co-dissemination demonstrated the importance of involving stakeholders directly.</li><li>• Co-presenting the results allowed the stakeholders for meaningful exchanges with their community.</li><li>• The research process was more accessible and relevant to the community of pwMS.</li></ul>

MUW, Medical University of Vienna; PAS, PPI Assessment Survey; PC, Participation Check; PPI: Patient and Public Involvement; pwMS, people with multiple sclerosis; RZM, Clinic for Rehabilitation Muenster; SAM, Self-Assessment Manikin; SD, Semantic Differential; USE\_MS, Unidimensional Self-Efficacy Scale for Multiple Sclerosis.