

Replicable Process for Developing a Research Agenda in Pediatric Multiple Sclerosis

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Replicable Process to Develop a Research Agenda for Pediatric Multiple Sclerosis

Background

In 2023, Accelerated Cure Project (ACP), a nonprofit organization with the mission to improve the health, healthcare, and quality of life for those affected by multiple sclerosis (MS) through facilitating research, launched a project to develop a multi-stakeholder research agenda for pediatric MS. ACP collaborated with youths diagnosed with pediatric MS, their family members, researchers, healthcare providers, and funders, to develop the research agenda.

This document describes the replicable process undertaken during the project, including key learnings and recommendations to enable other organizations to leverage a similar approach.

Process

Process Phase	Process Step	Notes
Project Planning		
Project Planning	Form a multi-stakeholder Steering Committee (SC)	The SC should include representation from each of the stakeholder groups with an interest in the resulting agenda. Our SC included ~12 members including project staff, youths with pediatric MS, at least one parent, researchers, healthcare providers, and a funder. The SC should meet periodically throughout the project to provide insights and feedback related to the overall process, and can be consulted over email or through other means between meetings.
Project Planning	Form a Planning Committee (PC)	Identify a subset of the SC who will make up the PC. The PC is responsible for developing the agendas for the convenings. The PC can call upon the SC for additional input and guidance, as needed. Our PC included a professional facilitator, 2 ACP staff members with scientific and operational expertise, 1 young adult who had been diagnosed with pediatric MS as a teen, and a funder with deep connections to the parent/guardian community.
Convening Planning		
Convening (#1) Planning	Define the Purpose, Outcomes and Processes	The Purpose (<i>Why we are gathering</i>), Outcomes (<i>What we are hoping to accomplish</i>), and Processes (<i>How we will accomplish our desired outcomes</i>) will guide all elements of the convening including who to invite, what the agenda should include, and what supporting materials are needed, among other elements. See

	(POP) for the 1st convening	Appendix A for the POP for our 1st convening.
Convening (#1) Planning	Identify potential 1 st convening attendees	Consider the stakeholder groups you will involve and the desired number of participants. For our 1st convening, we focused exclusively on the patient and family communities and engaged 25 participants for a 2-hour meeting.
Convening (#1) Planning	Select the date and time for the 1st convening	Gather availability from intended attendees, offering a selection of day, evening, and weekend times, if possible.
Convening (#1) Planning	Develop and deploy a registration survey to the potential attendees	Gather contact details, information about the participant and their relationship to the topic/disease, and solicit any questions they may have in advance of the convening.
Convening (#1) Planning	Develop the agenda for the 1st convening	Develop the agenda based on the POP you have defined. Consider the information you hope to gather from the attendees and the best approaches to ensure all voices are heard (breakout rooms, use of the chat feature, supplemental digital tools, etc.). See Appendix A for the agenda from our 1st convening.
Convening (#1) Planning	Send meeting details and any pre-reading to attendees	Provide meeting details (including the POP, a brief agenda, and how to access the meeting) in an easy to read format. If there is pre-reading required, provide ample time for participants to undertake the work and ensure the materials are written with the receiving audience in mind.
Convening Execution		
Convening (#1) Execution	Host the 1st convening	If holding the meeting virtually, remember to enable recording (with consent) so that transcripts can be easily developed.
Convening Post-Processing		
Convening	Provide a	Develop a brief survey (What went well? What didn't? Do you

(#1) Post-Processing	post-meeting survey to gather participant feedback	have any additional comments or questions?) to gather feedback from attendees. Provide the link to the survey prior to ending the convening and in a follow-up email.
Convening (#1) Post-Processing	Use transcripts to identify key themes	We used AI (Claude.ai) to identify the key themes and discussion points from the transcripts and then had each member of the PC review both the AI-generated information and the transcripts to ensure that no significant concepts had been missed and that the AI-generated reports were accurate. The key themes from our 1st convening represented the areas for potential research of highest priority to our patient and family attendees.
Convening (#1) Post-Processing	Send a post-meeting email/report to attendees	Provide attendees with a summary of the findings from the meeting and a link to the feedback survey. Encourage attendees to respond to the survey and/or via email especially if they believe any key themes were missed or incorrectly described. Include information about compensation (how it will be received), if applicable.
Convening Planning		
Convening (#2) Planning	Define the POP for 2nd convening	Use the key themes and other information from the 1 st convening to determine the outline of the 2 nd convening. See Appendix B for the POP for our 2nd convening.
Convening (#2) Planning	Identify potential 2 nd convening attendees, including researchers and clinicians	For our 2nd convening, we invited researchers and clinicians with interests in people-powered research to join the discussion. We also invited attendees from the 1st convening and those who had expressed interest in the 1 st convening but had been unable to attend.
Convening (#2) Planning	Select the date and time for the 2nd convening	Gather availability from intended attendees, offering a selection of day, evening, and weekend times, if possible.
Convening (#2)	Develop and deploy a	The output of the 1st convening will likely include topics that are: a) well-suited to comparative effectiveness/people-centered

Planning	survey to enable theme/ topic prioritizing	outcomes research (CER/PCOR); b) well-suited to research but not people-centered and c) important to stakeholders but more aligned with services, access, and advocacy. Request prioritization from stakeholders to align the content of the 2nd convening with the topics that are of the highest priority and likely to yield robust research questions that can be answered by CER/PCOR.
Convening (#2) Planning	Identify which topics to explore in 2nd convening	Using information gleaned from the stakeholder survey, identify the topics to be discussed in detail at the 2nd convening.
Convening (#2) Planning	Develop and deploy a registration survey to the potential attendees	Gather contact details, information about the participant and their relationship to the topic/disease, and request they identify the topics they, in particular, would like to discuss during the 2 nd convening. Also solicit any questions they may have in advance of the convening.
Convening (#2) Planning	Develop the agenda for 2nd convening	Develop the agenda based on the POP you have defined. For our 2nd convening, we established a breakout room for each of the 4 topics and staffed each room with a facilitator and 1 or more clinicians. Our patient and family member attendees were able to select 2 of the 4 breakout rooms to attend in order to participate in deeper discussions on the topics of greatest interest to them. See Appendix B for additional details and the agenda from our 2nd convening.
Convening (#2) Planning	Send meeting details and any pre-reading to attendees	Provide meeting details (including the POP, a brief agenda, and how to access the meeting) in an easy to read format. If there is pre-reading required, provide ample time for participants to undertake the work and ensure the materials are written with the receiving audience in mind.
Convening Execution		
Convening (#2) Execution	Host the 2nd convening	If holding the meeting virtually, remember to enable recording (with consent) so that transcripts can be easily developed.

Convening Post-Processing		
Convening (#2) Post-Processing	Use transcripts to identify the priority research questions for each topic/theme	We used AI (Claude.ai) to parse each transcript to identify the research questions discussed per topic in each breakout room and then had members of the PC review the AI-generated output and the transcripts to uncover any missed items and to ensure accuracy.
Convening (#2) Post-Processing	Provide a post-meeting survey to gather participant feedback	Provide attendees with a summary of the findings from the meeting and a link to the feedback survey. Encourage attendees to respond to the survey and/or via email especially if they believe any key themes were missed or incorrectly described. Include information about compensation (how it will be received), if applicable.
Convening (#2) Post-Processing	Develop the research agenda using the outputs from the 1st and 2nd convenings, including the entire set of key topics/themes and resulting research questions	The 1st convening, attended by the primary stakeholders of interest, will have generated key topics of high importance to them. The 2nd convening, attended by both the primary stakeholder group and including researchers and clinicians, will have enabled deeper discussions in some of the key topic areas. Document these findings (the entire set of key topics/themes and the resulting research questions) to enable sharing of these insights with a broader audience.

Lessons Learned

As this was ACP's first project developing a research agenda for pediatric MS, we gained valuable insights that can inform future efforts:

1. Extend the duration of each convening to allow for more discussion in balance with participant comfort and ability to participate.

2. Allow for more time between the 1st and 2nd convening to more fully explore the topics raised at the 1st convening and how they relate to comparative effectiveness research (CER) and patient-centered outcomes research (PCOR).
3. Engage the researchers more comprehensively between the 1st and 2nd convenings to gather their expertise more fully. Specifically, we would have benefited from working collaboratively with them to shape the topics raised at the 1st convening into discussion topics more closely aligned to CER/PCOR and potentially, to have identified some preliminary research questions.
4. Allow for more time after the 2nd convening to shape the resulting research agenda. In particular, our resulting agenda reflects the topics of highest priority to our youths and family members affected by pediatric MS but would have benefitted from a 2nd level of prioritization to more specifically identify the research questions that could form the basis for CER/PCOR.
5. Consider a 3rd convening or other approaches to source more specific research questions of priority and interest to our youth and family members.
6. Gather feedback from a broader group of stakeholders at different points throughout the project. While our youth and family members do represent a diverse group of stakeholders, outreach to an even broader audience may have informed our work more fully and reflected a greater representation of the pediatric MS population.

Next Steps

ACP and its iConquerMS Kids & Teens (<https://kidsandteens.iconquerms.org/kidsandteens>) initiative are available as resources and research partners to facilitate research in pediatric MS. We have learned a great deal from other organizations who engage people affected by diseases and caregivers in people-centered research, and have incorporated those learnings into our initiative and operations. Similarly, we are always open to sharing our expertise and insights with others. Please contact us via email at kidsandteens@iConquerMS.org if you have questions or comments related to research agendas or the process we have described in this document, or if you believe we could provide assistance in any other way related to people-powered and people-centered research.

Appendix A – Purpose, Outcomes, Processes and Agenda for 1st Convening

The 2-hour convening was held virtually via Zoom and was hosted by 4 Planning Committee members and attended by 25 participants.

The purpose, outcomes, and processes (POP) associated with the convening:

Purpose of this gathering – *Why we are we coming together today*

- Bring together kids and teens living with MS, and their siblings and parents/ caregivers, to share their priorities, hopes, and questions – to ultimately inspire and inform the future direction of pediatric MS research

Desired outcomes – *What we are trying to accomplish*

- Share and celebrate perspectives and experiences of kids & teens living with MS and their family members
- Participants feel like their voices and perspectives matter
- Participants understand the purpose of this gathering and how their ideas will be incorporated moving forward

Process – *How we will move through our time*

- Welcome and opening (full group)
- Overview of our time and approach (full group)
- Community Agreements (full group)
- Brainstorm/ word cloud activity (full group)
- Share stories, envision the future, consider research (in breakout rooms: 1 for kids & teens living with MS, 1 for siblings, and 2 for parents/ caregivers)
- Share out and moving forward (full group)
- Wrap up, check-out, and closing (full group)

The full agenda for the meeting:

[*Times are approximate and will vary based on number of people, and their energy and engagement]

*Time	Agenda item	Notes
2:30pm ET/ 1:30pm CT [30']	Open Zoom room, facilitators get settled	Play background music (Daniel)
3pm/ 1pm [10']	1. Welcome and opening check-in <ul style="list-style-type: none">● Possible prompt: Please share your name, where are you zooming in from, and what is one of your favorite (or least favorite!) things about this time of year?	In CHAT & SLIDE: Prompt & Slide As people arrive, facilitators welcome them verbally and in the Chat Enter check-in prompt in the Chat

<p>3:10/ 1:10 [5']</p>	<p>2. Overview of our time and how we will engage (Daniel)</p> <ul style="list-style-type: none"> ● Intro of Sara, Hollie, & Krista and their organizational affiliation and roles – set tone of we’re here, we want to listen and learn ● Be clear what we mean by “research”, set parameters – could be future conversations (Hollie) ● We are not medical providers, type of information we are discussing/ sharing/ inviting is about lived experience, not to provide medical insights ● Our focus is on research – we hope that people might turn to each other as supports outside of this space; we will send you follow-up resources ● How to interject if you have any questions – use Chat box as, and we will monitor it (Daniel) ● Recording – we will use it to go back and make sure we are capturing people’s ideas accurately, help guide future planning, won’t share it beyond internal team – check for agreement 	<p>SLIDES: Agenda, simple def of research (process of asking question about something you want to know... MS research includes drugs and other things... often questions emanate from doctors/ scientists - and we are trying to shift that!)</p> <p>Krista to monitor Chat box</p> <p>Be sure to touch on –</p> <ul style="list-style-type: none"> - Express appreciation for everyone’s presence, especially on a Sunday - Acknowledge the impact of MS on everyone’s lives in big and small ways - We are together for almost 2 more hours, and we will be together in full group to start and then go further in sharing ideas and experiences with peers in smaller groups, and then come back together
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<p>3:15/ 1:15 [10']</p>	<p>3. Community Agreements</p> <ul style="list-style-type: none"> ● Review what we mean by “Community Agreements” and share sample list → ● Check for clarity – do we all understand what these mean? ● Check for additions – what else might we need from ourselves and the group to participate today as fully as we want? ● Check for agreement – are we willing to try these together? <p>And:</p> <ul style="list-style-type: none"> ● Affirm language that everyone consents to participating and is joining voluntarily – ● If you have any accessibility needs, accommodations that might be useful, and/ or technical issues, please contact... <ul style="list-style-type: none"> ○ Text Hollie 	<p>Sample list to start with (on SLIDE and in Chat):</p> <ul style="list-style-type: none"> ● <i>Be you, and share your truth and experience at the level you are ready, willing, and able</i> ● <i>Listen for understanding and learning</i> ● <i>Lean into curiosity and ask all questions</i> ● <i>Share the air</i> ● <i>Honor the perspectives and experiences of others, including those that might be different from your own</i> ● <i>Honor confidentiality - gain the learning and leave the stories and details</i> ● <i>Take care of yourself and others as needed, including going off camera, getting up and</i> ● <i>Use virtual “Parking Lot” for questions and ideas</i>
<p>3:25/ 1:25 [5']</p>	<p>4. Full group brainstorm/ word cloud activity</p> <ul style="list-style-type: none"> ● Prompt: Please fill in the rest of this sentence as many times as you want – “MS is...” ● Review word cloud together 	<p>Daniel set up in Mentimeter (or similar platform) and share link</p>

<p>3:30/ 1:30 [60']</p>	<p>5. Breakout rooms – SEE BELOW for details</p> <ul style="list-style-type: none"> ● Kids/ Teens with MS, with Sara ● Siblings, with Krista ● Parents/ caregivers (two groups), with Daniel and Hollie 	<p>Facilitators should be capturing notes during each breakout</p> <p>Process notes to review in each group:</p> <ul style="list-style-type: none"> - Be clear at the outset that we will be inviting participation to prompts overall, and when we are inviting everyone to respond, we will do a go-round in alpha order by first name – and people always have the right to pass - Be clear that we have limited time together – the buckets we are really hoping to explore: If you were putting together your own pediatric MS research agenda... <ul style="list-style-type: none"> - With parents/ caregivers, name that there is not another space we know of that is pulling together families to be a voice around research, and, to do that most successfully, we will be moving in this way...
<p>4:30/ 2:30 [10']</p>	<p>6. Return to the full group</p> <ul style="list-style-type: none"> ● Welcome back! ● Share out (starting with kids/ teens) – Prompt: What is a headline, highlight, or other bright spot from your experiences in your breakout room? 	

<p>4:40/ 2:40 [5']</p>	<p>7. Moving forward:</p> <ul style="list-style-type: none">● What happens with the ideas we created? How can we add to them?● What's next – moving toward developing research agenda (including next gathering, coming in February)<ul style="list-style-type: none">○ We will come back to them as we move toward Feb gathering○ We convened a smaller group in Dec, and here is where we landed... now you have an opportunity to add to it...○ Empowering participants from this session to be open/ push back based on their experience...○ Potential for cross-pollinating breakouts to do deeper exploration between kids and researchers going deeper... i.e., sourcing ideas from Dec gathering..	
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<p>4:50/ 2:50 [10']</p>	<p>8. Wrap-up, check-out, & closing</p> <ul style="list-style-type: none"> ● We want your feedback – survey forthcoming... <ul style="list-style-type: none"> ○ Including: was there anything left unsaid/ that you thought about ● If you want to stay connected – Oscar the MS Monkey, NMSS, etc. ● The next gathering coming in February <p>Closing word cloud</p> <ul style="list-style-type: none"> ● Prompt: Please fill in the rest of this sentence as many times as you want – “MS will be...” <p>Closing go-round to bring everyone’s voice in:</p> <ul style="list-style-type: none"> ● What is one word to describe how you are feeling at the end of our time together? <p>Thank you!</p>	
<p>5pm/ 3pm</p>	<p>Adjourn</p>	

BREAKOUT ROOMS - details (and facilitators notice if/ when a break might be useful)

<p>Kids/ Teens with MS (Sara) - RECORD! Reminder</p> <p>→ Reminder about context for this is research...</p> <p>1. Welcome and introductions [5']</p> <ul style="list-style-type: none"> ● Preferred name, pronouns, where you live, age at diagnosis ● Recognition of wide range in ages and experiences, and importance of creating space for all – and is there anything else that will help us each participate? <p>2. Mood meter check-in [3']</p> <ul style="list-style-type: none"> ● How are you feeling right now? <p>3. Words/ images/ sensations of life with MS [4']</p> <ul style="list-style-type: none"> ● Using Chat or Whiteboard please share some of the words, images, sensations of how you have been living with MS (could be a special word/ phrase your family has come up with - e.g., “ugly bugly”) ● Review together – what is catching people’s attention <p>4. Story-sharing: What is one important thing to know about the story of your experience leading up to/ since diagnosis? What is one</p>	<p>Siblings (Krista) RECORD! Reminder</p> <p>→ importance of validating sibling experience with MS, and they bring important perspectives! → Reminder about context for this is research...</p> <p>1. Welcome and introductions [5']</p> <ul style="list-style-type: none"> ● Preferred name, pronouns, where you live, age of sibling(s) <p>2. Mood meter check-in [3']</p> <ul style="list-style-type: none"> ● How are you feeling right now? <p>3. Words/ images/ sensations of having a sibling with MS [4']</p> <ul style="list-style-type: none"> ● Using Chat or Whiteboard please share some of the words, images, sensations of how you have been living with MS (could be a special word/ phrase your family has come up with - e.g., “ugly bugly”) ● Review together – what is catching people’s attention <p>4. Story-sharing: What is one important thing to know about the story of your experience having a sibling with MS? [18']</p> <ul style="list-style-type: none"> ● What is one rose (something positive or 	<p>Parents/ caregivers (split into 2, Hollie in breakout, Daniel in main room) RECORD! Reminder</p> <p>→ Reminder about context for this is research...</p> <p>1. Welcome and introductions [5']</p> <ul style="list-style-type: none"> ● Preferred name, pronouns, where you live, age of child/ren, age at diagnosis... <p>2. Mood meter check-in [3']</p> <ul style="list-style-type: none"> ● How are you feeling right now? <p>3. Sharing lived experience [20']</p> <ul style="list-style-type: none"> ● What is a rose/ bud/ thorn of your experience of being a parent/ caregiver to a kid/ teen with MS? (Rose = something positive and/ or beautiful; Bud = something new, still forming, and/or emerging; Thorn = something challenging or hard) ● What do you know/ want to know about MS and MS research? What is one of your biggest unanswered questions? <p>4. Envisioning a future in which kids/ teens living with</p>
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<p>important thing to know about your life now? [18']</p> <ul style="list-style-type: none"> ● Possible additional prompt: <ul style="list-style-type: none"> ○ What is a superpower that you have developed/ are developing? ● What is a wish you have for yourself and your peers? What is a worry? ● What is one of your biggest unanswered questions? <p>5. Envisioning a future in which kids/ teens living with MS and their families have what they need [20']</p> <ul style="list-style-type: none"> ● If you had a magic wand, what is one thing you might change about living with MS? ● If you were given \$10m to invest in MS research/ treatment, where would you put it? <p>6. Headlines/ highlights/ bright spots [7'] Facilitator: capture/ share a few ideas as examples</p> <ul style="list-style-type: none"> ● What are a couple of ideas we want to share with the other groups to know about our experience in this breakout? ● Who is willing to share these aloud in the full group (could be a with the facilitator, with a peer, alone) 	<p>beautiful)? What is one thorn (something challenging or hard)?</p> <ul style="list-style-type: none"> ● What is a wish you have for your sibling and other kids/ teens living with MS? What is a wish you have for yourself? What is a worry? ● What is one of your biggest unanswered questions? <p>5. Envisioning a future in which kids/ teens living with MS and their families have what they need [20']</p> <ul style="list-style-type: none"> ● If you had a magic wand, what is one thing you might change about living with MS? ● If you were given \$10m to invest in MS research/ treatment, where would you put it? <p>6. Headlines/ highlights/ bright spots [7'] Facilitator: capture/ share a few ideas as examples</p> <ul style="list-style-type: none"> ● What are a couple of ideas we want to share with the other groups to know about our experience in this breakout? ● Who is willing to share these aloud in the full group (could be a with the facilitator, with a peer, alone) 	<p>MS have what they need [20']</p> <ul style="list-style-type: none"> ● Given what you know right now, what are you most hopeful for your child/ in the future? ● Given everything we have discussed today, if you were given \$10m to invest in pediatric MS research/ treatment, how would you prioritize/ where would you put it? ● AND: What is one radical idea you have for MS research? <p>5. Headlines/ highlights/ bright spots [7']</p> <ul style="list-style-type: none"> ● What do we want the children to know about our experience in this breakout? ● Who would like to volunteer to share this with the full group? <p>6. Closing: What are we grateful for about this time together? [5']</p>
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<p>7. Mood meter check-out [3']</p> <ul style="list-style-type: none">● How are you feeling about our time together? <p>Ideas for peers to attend Feb gathering?</p> <p>Thank you!</p>	<p>7. Mood meter check-out [3']</p> <ul style="list-style-type: none">● How are you feeling about our time together? <p>Thank you!</p>	
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Appendix B – Purpose, Outcomes, Processes, and Agenda for 2nd Convening

Details

The 2 1/2-hour convening was held virtually via Zoom and was hosted by 5 project team members and attended by 25 participants.

The purpose, objectives, and processes associated with the convening:

Purpose of this gathering – *Why we are we coming together today*

- Bring together families affected by pediatric MS with researchers to inspire and inform the future direction of pediatric MS research by developing a prioritized research agenda. Our discussion will build from the questions and ideas from our December gathering, when 25 people came together to share their perspectives and experiences of living with pediatric MS.

Desired outcomes – *What we are trying to accomplish*

- Youth and families with MS understand more about the research process, how ideas can turn into research, and their role(s) in people-centered research
- Researchers have a better sense of the research priorities and preferences of kids and families with MS
- Participants contribute to a prioritized list of topics/ questions sourced by kids and families with MS, and strengthened by collaborative discussion that reflects the collective wisdom/ expertise of kids and families affected by MS and researchers
- Participants have an understanding of how topics covered here will be leveraged to create a prioritized research agenda to move research forward
- Participants have shared enthusiasm and energy to move this work forward in different ways

Process – *How we will move through our time*

- Welcome and opening check-in (full group)
- Overview of our time and how we will engage (full group)
- Community Agreements (full group)
- Full group overview: Context-setting; Practice with the approach similar to what we will use in breakouts (full group)
- Breakouts round 1 (in breakout rooms by topic: Symptoms and relapses; Mental health; Fatigue and cognition; Diet and wellness)
- Breakouts round 2 (in breakout rooms by topic: Symptoms and relapses; Mental health; Fatigue and cognition; Diet and wellness)

- Share out and moving forward (full group)
- Wrap up, check-out, and closing (full group)

The full agenda for the meeting:

[*Times are approximate and will vary based on number of people, and their energy and engagement]

Time*	Agenda item	Notes
2:30pm ET/ 1:30pm CT [30']	Open Zoom room, facilitators get settled · <i>Invite people that are not-confident Zoom users to arrive early and get support</i>	Play background music (Daniel)
3pm/ 2pm [10']	1. Welcome and opening check-in (CHAT) · Possible prompt: Please share your name, where are you zooming in from, and what is one of your favorite (or least favorite!) things about this time of year?	As people arrive, facilitators welcome them verbally and in the Chat Enter check-in prompt in the Chat

3:10/ 2:10
[5']

2. Overview of our time and how we will engage
- Intro of Sara, Hollie, & Krista and their organizational affiliation and roles – set tone of we're here, we want to listen, and learn
 - Invite people that were here in December to raise hands — and appreciate their participation then and now
 - Intro of researchers joining us
 - In reviewing the purpose, outcomes, and agenda, clarify what we mean by “prioritized research agenda”

- Be sure to touch on
- - Express appreciation for everyone's presence, especially on a Saturday
 - Acknowledge the impact of MS on everyone's lives in big and small ways, and the shared commitment to addressing it
 - Affirm/ appreciate the significance of collaboration between family members living with MS and MS researchers – this is a unique event people are participating in!
 - We are together for 2.5 hours, and we will be together in full group to start, have time to select smaller breakout groups to go deeper in considering research

question, then
come back
together as full
group, and have
time for break

3:15/ 2:15
[5']

3. Community Agreements

- Review what we mean by “Community Agreements” and share list from December
→ → → →
- Check for clarity – do we all understand what these mean?
- Check for additions – what else might we need from ourselves and the group to participate today as fully as we want?
- Check for agreement – are we willing to try these together?

And:

- Check that everyone consents to participating in the session
- *If you have any accessibility needs, accommodations that might be useful, and/ or technical issues, please contact...* [Hollie willing, and is there someone else that might be available?]

Agreements (on slide and in Chat):

- *Everyone attending this brings equal importance to the table... it takes all of us working together to make things happen both during this session and advancing pediatric MS research*
- *Be you, and share your truth and experience at the level you are ready, willing, and able*
- *Listen for understanding and learning*
- *Lean into curiosity and ask all questions*
- *Share the air*
- *Honor the perspectives and experiences of others, including those that might be different from your own*
- *Honor confidentiality - gain the learning and leave the stories and details*

3:20/ 2:20
[25']

4. Full group overview: Context-setting; Practice with the approach similar to what we will use in breakouts; Review of poll results

[5'] Context setting –

- BRIEF overview of what research process looks like, why a “research agenda” is created, what happens with it, and what possible outcomes could be with this particular research agenda that we are contributing to... (SARA)
 - Dependent on who picks up a topic, how it’s funded and carried out, what role(s) might be available for families to play (and when that could be)
 - Mention Pediatric MS Network? (ask Yolanda)
- Hear from researcher(s) how patient/ family voices have informed other research efforts (current or past) (LANA or NICK)
 - affirmation that patient/ family voices are valued and heard
- Invite any clarifying questions from young people/ families

[10'] Practice^ –

A couple of options:

- A. Use a less highly ranked topic from poll (e.g., *Increasing public knowledge and understanding of pediatric MS*)

[4'] Review poll results –

- Review 4 topic areas we will be discussing and that there will be two rounds of breakouts with each of the 4 topics
- Assign family members to topic(s) that they pre-selected and/or invite family members to self-select into a topic/ question that they prioritized
- Reminder: we want to facilitate a collaborative conversation and co-creation between families living with MS and researchers to identify questions that matter

- Reiterate that the ideas we share and discussions we have during this session will inform the development of a prioritized “research agenda”

Is there a short video – what is research?

IN advance:

- Send out as part of advance materials a glossary... this is what we mean by:
 - Prioritized research agenda
 - Research process
- Send out report from first gathering to all participants

^Practice option process details:

A. Topic

- Introduce prompt such as: “How might we...” or “It

to them and that could inform research moving forward within the topic area

might be helpful/ make a difference if we..." and provide example of a possible response

- Invite people to come up with one first draft idea – any/ all ideas good, we are just practicing!

- Chatterfall: When prompted, ask people that are able to put their one idea in Chat (or other platform?)...

- Read all ideas aloud

- Introduce "Ditto!" and "Yes, and..." and invite people to select one idea to either *Ditto* (i.e., they like it as-is) or *Yes, and...* (i.e., they have a way to improve on it), and, when prompted, enter in Chat

3:45/ 2:45
[35']

5. Breakouts round 1

Overview – our breakout time will include:

- Introductions and “Either/ Or” ice breaker, e.g.:
 - Cat or dog?
 - Ice cream or cookies?
 - Winter or summer?
- Framing of the overarching topic – wanting to get to what you really want to know, what are the questions that are most important to you?
- Family members develop first draft response to “How might we...” or “It might be helpful/ make a difference if we...”
 - Drop them in the Chat!
 - And feel free to share why it is an important question to you!
- Researcher(s) and family members together build on family members’ ideas by responding to “Ditto”/ “Yes, and...” prompt
- As possible/ time permits: Family members + researcher/s build towards one or more specific questions that matter to them within the topic

REMIND

FACILITATORS TO RECORD!!!

- Each breakout room will have a facilitator (Hollie, Krista, Sara, Daniel) and at least one researcher
- Facilitators should be capturing notes during each breakout

Process notes to review in each group:

- Be clear at the outset that we will be inviting participation to prompts overall, and when we are inviting everyone to respond, we will do a go-round in alpha order by first name – and people always have the right to pass
- Be clear that this time together is for collaborative conversation and co-creation to drill down together on a

		topic/ question with questions that matter to them
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4:20/ 3:20 [10']	BREAK	Time for facilitators to gather
4:25/ 3:25 [10']	6. Return to the full group <ul style="list-style-type: none"> · Welcome back! · Transition to Breakouts round 2: Assign family members to topic(s) that they pre-selected and/or invite family members to self-select into a topic/ question that they prioritized 	Time to get people to breakouts...
4:35/ 3:35 [35']	7. Breakouts round 2 <ul style="list-style-type: none"> · Starting fresh with this group 	
5:05/4:05 [10']	6. Return to the full group <ul style="list-style-type: none"> · Welcome back! · Moderator share what emerged from both groups about that topic area and where they landed with their questions · Invite, in Chat, additional “Yes, ands...” from the rest of the group 	
5:15/ 4:15 [5']	7. Moving forward: <ul style="list-style-type: none"> · What happens with the ideas we generated? · What’s next with process of developing “prioritized research agenda”? · What can participants expect in terms of follow-up moving forward? 	
5:20/ 4:20 [10']	8. Wrap-up, check-out, & closing <ul style="list-style-type: none"> · We want your feedback – survey forthcoming... · If you want to stay connected – Oscar the MS Monkey, NMSS, etc. <p>Closing go-round to bring everyone’s voice in:</p> <ul style="list-style-type: none"> · What is one word to describe how you are feeling at the end of our time together? <p>Thank you!</p>	
5:30pm/ 4:30pm	Adjourn	