



Best Practices for Successful Care Partner Engagement for Research

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Background

In recent years there has been a welcome shift towards patient-centricity in both research and care. As the role of people affected by health conditions, including patients and care partners, moves from “research subject” to “research partner”, the considerations for successful engagement increase considerably. Whereas once the role was limited to enrolling in the research study, participants are now assuming collaborative responsibilities in all phases of research, from deciding what gets studied, how it gets studied, and how the evidence generated is disseminated. From the development of prioritized research agendas, to contributing to all facets of study design and conduct, to designing and conducting communication strategies to disseminate results and evidence, patients and families are driving the research process. The expansion of the patient and care partner role and the increase in engagement touchpoints require new and expanded engagement strategies and tools, and the development of best practices.

Care partners may hold multiple roles as research partners. In addition to participating in and partnering on research to address the needs and priorities of care partners themselves, they may also hold important roles as observers and contributors to research focused on the needs of their loved one. Caregivers in this role may not only provide information during the conduct of a research study as an observer to their loved one but may also be “research partners” and contribute to the prioritization, design, and conduct of research for direct benefit of those living with the health condition.

Additional complexity is introduced when the research partnership is conducted virtually and is absent the face-to-face component found in on-site clinic-based research. As the research enterprise moves towards an acceptance of decentralized trials and the worlds of research and care migrate towards virtual offerings, engagement strategies must evolve to adapt and overcome the challenges implicit in non-face-to-face engagement. What might be easily communicated for research conducted “in person” or at a clinical site now takes on additional complexity and nuance through the virtual realm.

This document will not delve deeply into the overall best practices for engagement of people affected by health conditions in research, but will focus instead on considerations specific to engagement of caregivers, both for the purposes of partnering on caregiver-focused research and as observers and contributors to research for the benefit of their loved one.

iConquerMS, the Multiple Sclerosis People-Powered Research Network

The iConquerMS initiative was launched in 2014, and was the first wholly virtual research network for multiple sclerosis (MS). Membership in and of itself in iConquerMS does not constitute research. Once enrolled, members are invited to participate in REAL MS, the initiative's longitudinal research study collecting data related to demographics, health history, quality of life, and other topics. In addition, the initiative's members are frequently invited to participate in other opportunities as research partners. Members might be asked to respond to *ad hoc* surveys instantiated on iConquerMS or other survey platforms, participate in focus groups or councils, submit their research priorities and needs via the iConquerMS portal, or participate in online community discussions, among other activities.

Since the launch of iConquerMS, we have developed and refined strategies for engagement of adults affected by MS as true partners in MS research. People affected by MS are invited to engage as members of iConquerMS and to contribute their expertise and insights in all phases of research from the identification of what topics should be studied (through the "Our Questions Have Power" component of the initiative), to contributing to study design, to managing the conduct of research, through to dissemination. iConquerMS members with an interest in contributing even more substantially as research partners are invited to participate in focus groups, serve as members of task forces and steering committees, and to serve as members on iConquerMS's governance, including our governing board, engagement committee, and research committee. While MS caregivers are eligible to join iConquerMS and to participate in a variety of roles, until now there have been no efforts dedicated to address the specific needs of the MS care partner population as research partners through iConquerMS.

As we expand the population of iConquerMS participants to include MS caregivers, we must expand our engagement strategies to accommodate their unique needs and interests. Our exploration as to the best practices for care partner engagement in research will provide guidance for work conducted under this Engagement Award as we seek to intentionally include MS caregivers as full partners in iConquerMS.

Methods

In order to develop this summary of best practices for care partner engagement in research, we have:

- Engaged with some of our People-Powered Research Network colleagues from the PCORI-funded PCORnet 1.0 initiative and the more recent Learning Network who involve caregivers as research partners;
- Reviewed PCORI-generated tools for engagement including the Engagement Rubric¹ and other resources as available in the PCORI Engagement Tool and Resources Repository²;

- Discussed care partner research and engagement solutions with selected disease-focused organizations to learn more about their efforts with the caregiver populations and with organizations focused on providing support and services to caregivers;
- Conducted a literature review on methods and approaches to caregiver engagement for the purposes of research partnership; and,
- Considered how the information gleaned during the above activities applies to the iConquerMS initiative.

We will continue to evolve our understanding and application of best practices throughout the Engagement Award period and beyond.

Best Practices for Patient Engagement for the Purposes of Research

As previously mentioned, this document will focus primarily on considerations unique to the engagement of caregiver populations and will not delve deeply into considerations to be applied those living with health conditions, though there are clearly common approaches to be explored and undertaken. We have reviewed and will continue to explore best practices for overall engagement including synthesized literature reviews^{3,4} and other publications⁵ on the topic of engagement and will apply our findings to the overall conduct of the project and the iConquerMS initiative.

Considerations for Successful Caregiver Research Engagement

Consideration: Provide Leadership Opportunities for Caregivers

Including people who are affected by the health condition under study (such as those living with MS and their care partners) in leadership and decision-making roles is a best practice to be upheld. As we have developed the roster for this project's Steering Committee (SC), we have included eight care partners, representing a variety of carer relationships. Their contributions are as valuable as those of the "professional" members of the SC and will infuse the project with their lived experience and resulting insights. Ensuring that these care partners have clear, distinct, and impactful voices in all aspects of the initiative's design and conduct is a best practice.

Consideration: Provide Education and Training to Ensure Successful Participation

Providing education and training to those affected by health conditions to enable their full participation as research partners is critical to successful collaboration. Members of governing bodies, steering committees, task forces, and of initiatives such as iConquerMS are better able to contribute their insights and expertise and to engage as full partners when they are educated as to the expectations and responsibilities of their role. Ensuring that the educational tools contain imagery and content geared toward caregivers and are presented in formats that are engaging and facilitate learning will contribute toward their successful use.

Consideration: Include Caregiver Insights in All Aspects of the Initiative's Design and Operation

A research initiative that includes full engagement of people affected by a condition as partners requires the incorporation of their insights throughout all stages of the initiative's design and conduct. The research initiative should gather and include the perspectives of

care partners at every stage. The modifications to be made to the iConquerMS initiative to support and include caregivers as research partners will be made with the insights and guidance of our SC members.

Consideration: Enable Meaningful and Impactful Research

People affected by health conditions, including caregivers, are more likely to be engaged as research partners and participants when they view the research in question as meaningful and impactful. Including caregivers from the earliest phases of research, including in the development of prioritized research agendas, is critical to identifying research topics and questions of highest importance to them. We will work with our SC members to ensure that caregivers are well equipped to contribute to the elements of iConquerMS that focus on the identification and prioritization of research topics, such as the Our Questions Have Power component of the iConquerMS initiative, to ensure that the resulting research agendas reflect their priorities and interests.

Consideration: Highlight the Unique Value of the Caregiver Partner

An important component related to engagement is the ability to communicate the unique and meaningful role to be played by the caregiver in research. Whether engaged as a research partner for research focused on and to benefit caregivers, or as observers to the person living with MS, each caregiver has the opportunity to contribute to research in meaningful ways. Ensuring the unique and valuable role to be played is clearly communicated is best practice for engagement.

Consideration: Develop Communications Materials in Collaboration With Caregivers

Developing clear and engaging communications collateral is a critical component in support of successful research engagement. When considering the development of such material geared toward the caregiver population, it is important to develop materials specifically geared towards them. It is insufficient to repurpose materials developed for the those living with MS. We will rely on our SC members and other caregivers involved with the project to assist in the development of materials geared toward the MS caregiver populations. From additions to the iConquerMS website, to emails, social media content, and other content, we will ensure the information is developed in collaboration with our lived experience advisors and reflects their views.

Consideration: Identify Communication Channels That Meet the Caregiver Population Where They Are

Successful engagement of the caregiver population will require expansion of the communication channels used. The outreach currently conducted by iConquerMS is focused on those living with the disease and while reaching caregivers through the population of those they care for is one avenue of engagement, we will expand our outreach to include in-person and virtual groups directly supporting caregivers.

Consideration: Design Engagement Opportunities with the Realities of the Caregiver Experience in Mind

Opportunities for engagement as research partners must take into consideration the significant responsibilities and schedule and time constraints faced by most caregivers. All research partnering roles, whether as SC members, iConquerMS participants, or participants in a research study, must provide for flexibility, limit the placing of additional burdens on the caregiver, and allow for participation while minimizing impact on the caregiver's time and schedule. Designing these roles and their supportive processes with input from caregivers is an important first step but even asking for this input is an additional burden. Allowing for participation to be asynchronous, ensuring that engagements are highly meaningful, and providing value back to caregivers may mitigate some of the constraints. An important element for designing the modifications to iConquerMS to support caregivers will be to gather caregiver insights and suggestions as to how their participation as partners can be as seamless and low burden as possible while still providing value and satisfaction.

Consideration: Engage Caregivers as Ambassadors and Trusted Voices in Communicating with Others

Members who are successfully engaged as research partners are often compelling communicators and ambassadors to encourage others to consider participation. Enabling MS caregivers to share information about their participation with others will likely be a successful engagement strategy. These trusted voices will add credibility and increase trust with the unenrolled.

Consideration: Engage Other Stakeholders Who Are Known and Trusted

Caregivers to patients with health conditions rely on health care providers, nonprofits focused on the condition in question, nonprofits focused on caregiving in general, and others stakeholders, for support, services and information and view these entities with trust. Including these stakeholders in developing the initiative and in support of research engagement will provide additional support to the caregiver participants.

Consideration: Plan to Support External Researchers Who Will Engage With the Caregiver Population

Internally developed policies and resources to engage with the caregiver population are important to ensure successful research engagement. For an initiative like iConquerMS that also provides opportunities for our members to engage with external researchers, it is incumbent upon us to ensure those engagements are as successful as possible. In addition to preparing our caregiver members for external engagements through education, training, and information, we will also develop materials and policies that are supportive of the external researchers. We will ensure they understand best practices for engaging with our caregiver members and provide them with the supports they need to do so.

Summary and Looking Forward

Best practices associated with engaging MS caregivers include considerations that are applicable to all who participate as research partners, and considerations unique to the caregiver population. As we embark on the intentional inclusion of MS caregivers as members of iConquerMS, we will apply our learnings related to these engagement best practices and continue to learn from others successfully engaging caregivers as partners.

We will update this document as needed throughout the course of the project and as new insights and findings are gleaned.

References

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