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RESEARCH DISSEMINATION TO UNDERREPRESENTED GROUPS WITH MULTIPLE SCLEROSIS

BARRIERS, FACILITATORS, AND RECOMMENDATIONS FOR RESEARCHERS AND CLINICIANS

WHAT'S INSIDE

INTRODUCTION

Dissemination and communication of research study progress and results are fundamental components of multiple sclerosis (MS) research. Sharing of research results with the lay community is not only an ethical obligation, but it also significantly contributes to overall research progress by facilitating greater connection with diverse MS communities, improving public engagement and trust, informing policy, and ensuring research has a substantial impact on societal, systemic, and economic realms. What's more, research participants want to hear about results gathered from the studies they volunteer in.[1-3] As such, there needs to be a paradigm shift in how researchers, institutions, and funding sources approach research so that it becomes a partnership with the communities we work with, rather than pure data and science.

Despite the substantial importance of research dissemination, most studies fail to engage in this aspect of the research pipeline, often citing considerable barriers, especially related to historically minoritized communities. Barriers identified include: a lack of acknowledgement of dissemination activities and importance, absence of early planning, absence of financial support, logistical difficulties (e.g., limited staff, regulations), uncertainty of what to share and to whom, lack of incentives or diffusion of responsibility, timing of releasing results pre- or post-publication, ethical concerns, and an unclear understanding of how to connect with a non-research audience.[4-7] Specific barriers related to minoritized groups included translation into other languages, limited understanding of diverse cultures and cultural expectations, difficulty connecting with diverse communities, and limited inclusion of minoritized groups.[8-9]

Scientists have many incentives to publish results in scientific journals and disseminate results to the broader scientific community through academic conferences, talks, etc. However, incentives are lacking for research dissemination to lay communities or community outreach. In fact, even when institutions and funding sources require dissemination of results with past participants or lay communities, there can be a lack of accountability or follow through.

> ***There needs to be a paradigm shift in how researchers, institutions, and funding sources approach research so that it becomes a partnership with the communities we work with, rather than pure data and science.***

There is hope, however, as researchers can leverage a range of facilitators to disseminate their research to diverse communities, including preparing for research dissemination early on, collaborating with community partners/stakeholders, using multiple methods to disseminate research findings (e.g., website, social media), accessing educational opportunities to understand the history, climate, culture, and values of their participants, and forming symbiotic relationships with participants/communities.[8, 10-11] Having access to a set of “best practices” for disseminating research to minoritized groups with MS would also help to facilitate the sharing of results. While the most effective communication strategies and best practices for sharing of results with MS patients belonging to underrepresented communities continue to be a moving target, the goals of this guidance document are to acknowledge that barriers exist and to provide a list of tools and resources to aid in sharing back research results with MS research participants and people affected by MS belonging to minoritized communities.

As such, the current document serves as a starting point for:

- Understanding why research dissemination, especially to historically minoritized communities, is so important
- Better understanding barriers to research dissemination and how to overcome them
- Guidance for communicating your research to the lay community
- Resources for research dissemination, including possible outlets and examples of studies that have successfully disseminated study progress and results

THE IMPORTANCE OF RESEARCH RESULTS DISSEMINATION WITH UNDERREPRESENTED COMMUNITIES

There are many reasons to share study findings with the MS community, especially those from historically minoritized groups. Several of those reasons are listed below, many of which were gathered from a survey exploring researchers' perceptions and experiences regarding dissemination of study results.[8, 12]

REASON 1: ETHICAL OBLIGATION

In the health researchers survey, 15% of the participants mentioned ethics in their responses, with one stating that "on an ethical level, it is just and fair to provide results to participants," and another commenting that "I am ethically bound to disseminate information from research studies that I conduct."

REASON 2: ACCESSIBILITY TO THE PUBLIC

Members of the public typically do not visit PubMed or read academic journals. In addition, even if members of the public want to access academic resources, they are faced with barriers like paywalls. Therefore, the community at large may never learn about or see study results unless researchers make result sharing a priority in ways that are easily accessible, understandable, and effective.

REASON 3: RECIPROCITY

Sharing results is one form of returning value to the participants who donated their resources to the scientific community and therefore have a direct interest in learning the results. As stated by one respondent in the health researchers survey: "Participants donate their time, their resources, their bodies, and their health records... It is their right to have access to those results in aggregate and our responsibility to share them."

Sharing results that are actionable at the individual level can have an even bigger impact. A *Research Match survey*[3] asked participants what type of results were most important to receive; "results directly related to their health or the health of a loved one" were ranked the highest.

Providing research findings to participants and their communities also promotes reciprocity at the societal level and contributes to transparency. According to one respondent, "Public funding comes with responsibility to determine results and improve healthcare. This includes communicating with the public about study results."

REASON 4: BENEFITS TO RESEARCH

Sharing results with participants and communities helps to build trust in science and enhances the possibility of more widespread and representative participation in the future. For example:

- Pre- and post-surveys from community listening sessions held to disseminate research findings showed that these sessions increased the perceived advantages of clinical trials and increased trust in medical researchers.[16]
- Participants in a clinical trial cohort (90% Latino, 10% Black/non-Latino) indicated via survey that receiving the trial results (by text summary, video and/or infographic) *increased* their willingness to participate in future research.[17]
- *Multi-stakeholder forum discussions* showed that failure to return research results was seen as contributing to a feeling that "their time and efforts contribute to a research agenda that will not significantly or positively impact their own communities."[10]

Researchers who make specific efforts to share their study results with minoritized communities are therefore helping to ensure more diverse and representative studies in the future.

OVERCOMING BARRIERS TO COMMUNICATING RESEARCH FINDINGS

Researchers may encounter roadblocks in communicating research findings to minoritized individuals living with MS. Below are several examples along with ways in which researchers can overcome these barriers.[4-6, 12,]

Barrier 1: Lack of Acknowledgement and Support for Dissemination Activities

Researchers have incentives and institutional support for publishing their results within the scientific and medical communities, but not for disseminating their findings to the patient community and underrepresented populations.

What researchers can do: Help to change how research dissemination to the community is viewed and supported. Educate yourself about your role as a researcher and your ethical obligation to the communities you work with. It's especially crucial to understand the history, climate, culture, and values of your participants if your research focuses on or has special relevance to a specific group. Incorporate the topic of dissemination into conversations with your lab, colleagues, and broader institution to ensure that dissemination is acknowledged and that you and those around you are well-educated about disseminating results, especially to underrepresented communities.

Barrier 2: Failure to Plan for Dissemination

Without a plan in place in advance for sharing results with the patient community, it could be very difficult or impossible to find the time and resources to disseminate findings.

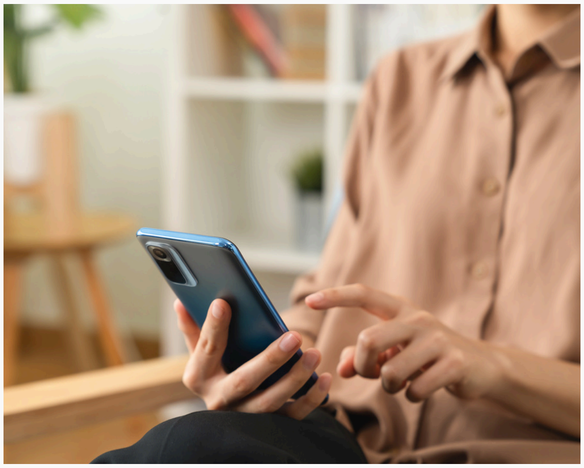
What researchers can do: Incorporate plans for dissemination from the very beginning of your grant and study planning. Refer to online resources that provide examples of guides that can be incorporated into grant applications or study protocols. Ask community members to provide guidance and feedback on your plan to ensure that it will be effective. By planning early, you can more easily address costs and potential barriers. Dissemination should not just be an afterthought; it should be an integral part of your study from the beginning.

Barrier 3: Non-disclosure agreements

If you are part of a multi-site, multi-investigator study, non-disclosure agreements may limit your ability to share the study findings with your local population.

What researchers can do: Work closely with your sponsor to discuss balancing data protection and transparency. Emphasize the benefits gained by the affected community from having access to the findings, and the benefits of building goodwill and trust in the study team and research community.

Barrier 4: Inability to contact participants after the end of the study



Ideally, research results should be provided to the actual study participants as well as with the community at large. However, it can be difficult to reach individuals if their contact information changes. In addition, direct contact needs to be pre-approved by the Institutional Review Board (IRB).

What researchers can do: Explore the option of using existing website space or creating a new space for hosting study results and providing this information to participants at the end of the study. This space can include a projected date for study findings to be posted. Because this strategy might not reach individuals with limited access to the internet, a computer, or a smartphone, or those with limited digital skills, you may consider consenting research participants to take part in an IRB-approved research repository that could allow contact by mail following the end of the study.

Barrier 5: Financial

If funding for dissemination isn't specifically included when the study budget is set, it will likely be very difficult to find these funds once the study is concluded and other priorities are demanding resources.

What researchers can do: Incorporate funds for research result dissemination as part of the grant application. If that isn't possible, explore low-to-no cost options, such as posting information on your own personal, lab, or departmental website, or working with existing MS communication channels to share your results. It may also be possible to find funding specifically for dissemination activities from public sources such as the National Institutes of Health (NIH) or Patient-Centered Outcomes Research Institute (PCORI), or private sources such as foundations. Although the process of applying for these funds does take time and effort, these resources can help ensure that your findings reach a wider audience and have more impact on health and quality of life.

Barrier 6: Lack of experience in translating research to the public

When communicating results to the public, it's important to use language and techniques that are accessible and understandable to a lay audience. However, this style of communication doesn't always come naturally to scientists.

What researchers can do: This document contains information on best practices in communicating study results in a tailored and approachable manner, and the following section includes information about specific types of communication formats with links to additional tools and resources. For those who are interested in general instruction on this topic, Collaborative Institutional Training Initiative (CITI) offers a *Communicating Research Findings* course for $29 which includes a module on communicating with the public.

Dissemination of results into other languages is also recommended. Be sure to use validated pipelines for translating documents from English into other languages (e.g., the Translation, Review, Adjudication, Pretest, and Documentation (TRAPD) method[13]) or with well-established groups that have extensive experience translating documents into other languages (e.g., FACIT Group[14]).

It is also a best practice to seek input and guidance from members of the groups that you would like to share your findings with. Maintaining cultural sensitivity and humility is paramount when working with groups to which you don't personally belong. Educate yourself on the communities you are working with, include community members in the dissemination process and pay them for their time, and give back to the community without expecting anything in return. Follow established guides for community engaged research and understand that you are responsible for upholding high ethical standards and making sure you are not just 'taking.'

Barrier 7: Participant harm

Researchers may be reluctant to share potentially sensitive results directly with the MS community if they fear there will be a negative reaction or unintended negative consequences.

What researchers can do: If you believe that your results may be distressing or cause anxiety among readers, consider providing connections to supportive resources, such as the National MS Society (support groups, peer connections) and SAMHSA's National Helpline. In addition, the IRB or ethics groups/consultants at your institution and/or community advisory members may be able to provide guidance on how best to approach potentially sensitive topics so that you are disseminating results in an informative yet sensitive way. Also, be sure to provide contact information so participants can reach out with questions.

GUIDANCE FOR COMMUNICATING RESEARCH RESULTS TO UNDERSERVED COMMUNITIES

We recommend considering the following factors when preparing to communicate your results to specific groups and communities.

Communication starts with a plan:

Develop a research results dissemination plan, ideally in conjunction with grant preparation and study design. If possible, include members of the community(ies) that you would like to share your results with in the planning process. Elements addressed in the plan should include, but not be limited to:

1. The purpose or goal of disseminating study results
2. The specific information to be shared
3. The target audience(s)
4. Selection of appropriate communication methods for each target audience. Considerations may include appropriate dissemination platforms for different stakeholders, languages, and level or complexity of the content to be shared. More information about formats and channels is provided below.
5. The frequency of outreach to the target audience(s), both during and upon study conclusion

Helpful guidance for developing dissemination plans can be found in these documents from the Agency for Healthcare Research and Quality, PLOS Computational Biology, and the National Institutes of Health.

Determine your target audience(s):

You may have multiple audiences to whom you desire to disseminate research results, and thus should consider each target audience and their needs when preparing to share your findings. Target audiences can be considered in terms of role, such as:

- People directly affected by MS:
  - People diagnosed with MS
  - Caregivers of persons with MS
- Professionals who are consumers as well as potential conduits of MS research results:
  - Health care providers (primary care providers, general neurologists, physical therapists, occupational therapists, social workers)
  - Healthcare providers specialized in MS care (MS specialists, MS nurses)
  - Advocacy group representatives

You may also want to define your target audiences in other ways, depending on the nature of the research, the local community, your awareness of specific community needs, etc.

Choose an open-access publication method, if possible:
For those members of the MS community who are able to locate and read medical journal articles online, being required to pay an access fee can be a substantial barrier. Publishing research results in an open-access journal or via an open-access model is recommended whenever possible. Note that for NIH funded research, the public has free access to the published study results no later than one year following publication.

Know how to communicate with your audience(s) and select an appropriate communication format:
After the target audience has been identified, it is important to determine the most appropriate communication strategy. Communication style, language, and presentation should be tailored to each audience. In a pilot study of past research participants, electronic communication (email) was identified as a preferred method to receive information by participants between the ages of 15 and 24.99 years and also by those aged 50 years and older.[15] However, preferences varied by age among other methods of communication. Other communication formats ranked as most preferred included written materials, opportunities for direct interaction with study teams, visuals (charts, graphs, and pictures), videos, audio recordings, and podcasts. The combined use of several methods to disseminate information is recommended.

Communication Formats

The following sections provide guidance on some common dissemination formats, and examples of how they have been used in specific research studies are included in a later section.

Infographics:

Infographics provide a way of summarizing a research study or specific aspects of a study in pictures as well as text. The inclusion of charts, graphs, and other images can help communicate important concepts more effectively and quickly than the paragraphs and tables that typically make up a scientific publication. Therefore, infographics can be an important tool in communicating research findings to diverse communities.

These resources provide helpful tips for creating infographics of research results, including links to tools and platforms that can help in generating these visual summaries:

- 5 Steps to Present Your Research in an Infographic
- How to Turn Your Journal Article into an Infographic
- Creating Effective Infographics and Visual Abstracts to Disseminate Research and Facilitate Medical Education on Social Media

Webinars:

Webinars offer an opportunity to maximize research dissemination and outreach efforts. Researchers could present research findings with the MS patient community and care partners, including underserved communities, by partnering with an MS patient advocacy organization that offers educational programs.

Best practices for communicating through webinars include tailoring the message to the audience, using narratives and visuals, and summarizing findings in a digestible way.

Webinars are typically one-hour long and offer the audience the opportunity to ask questions during the Q&A session. Webinars are recorded and then shared as on-demand videos.

Newsletters:

Many MS-related or health-focused organizations produce newsletters for their followers and constituents. These can be excellent channels for sharing your study results. Most organizations' newsletters are digital or have a digital version, so you can review past editions for the type of information they provide, and the communication style used.

Plain Language Summaries:

A plain language summary is a useful format for providing a succinct overview of a research study and its results. Plain language summaries are designed to make clinical study results accessible to the lay public. The following documents are useful when creating patient-friendly summaries:

- The Vanderbilt Institute for Clinical and Translational Research Guideline for creating narrative summaries
- Plain language summaries (PLS) of peer-reviewed publications and conference presentations: practical 'How-To' Guide for multi-stakeholder co-creation
- MRCT Center Return of Aggregate Results to Participants Toolkit

When writing plain language summaries, consider different levels of health literacy within each target audience, use patient-friendly language, and enlist the help of non-scientists to co-author or review the document. A recent study evaluated 60 randomized clinical trial lay summaries for readability; none were considered easy to read and >85% were considered difficult to read (Trial lay summaries were not fit for purpose).

The American Medical Association (AMA) and the NIH recommend that health materials be written at a 6th to 8th grade reading level. The Flesch-Kincaid Grade Level Test and the Flesch Reading Ease test are both included in Microsoft Word, and can be used to evaluate a document's reading level. While these tests are a valuable resource, they are not designed to determine if readers will understand medical terminology. Therefore, medical terms should be defined.

The NIH provides additional resources (Plain Language: Getting Started or Brushing Up) on the use of plain language when communicating.

Social Media:

Social media posts can be effective for sharing highlights of research findings and links to other resources where people can learn more. In addition to posting updates on your own accounts or institutional accounts, you can ask your community advisors to share updates with their followers. Your advisors may also be able to recommend individuals and organizations who are followed by the communities you hope to connect with and who may be willing to share research findings.

> ***It is important to determine the most appropriate communication strategy...Communication style, language, and presentation should be tailored to each audience.***

COMMUNICATION PARTNERS AND CHANNELS

Researchers can reach out to local and regional organizations that may be interested in partnering to disseminate research results. Such channels include church and religious groups/organizations, public libraries, MS support groups, sororities, local news stations, local community health fairs, local newspapers, and clinics (e.g., community health centers).

Additionally, the following MS patient advocacy organizations can help to share findings with individuals living with MS. When reaching out to these organizations, be sure to mention your goals regarding communicating with specific communities (e.g., minoritized communities), as they may have channels or methods that are particularly effective at connecting with these groups.

Potential organizations with which to partner with include, but are not limited to, the below.

National MS Society

https://www.nationalmssociety.org/

Sara Bernstein (sara.bernstein@nmss.org)
Manager, Research Information

The National MS Society reports on research findings that have either been published in peer review journals or presented at meetings. Although they report on both basic and clinical findings, they try to focus on research that is most relevant to the daily lives of people with MS. Their coverage usually starts with a news item (e.g., https://www.nationalmssociety.org/news-and-magazine/news). Their content team works together to disseminate research farther, sometimes with social media highlights, e-newsletters, the Momentum magazine, and/or webinars.

Multiple Sclerosis Association of America (MSAA)

https://mymsaa.org/

Andrea Griffin (agriffin@mymsaa.org)
VP of Communications & Marketing

MSAA publishes details on a limited number of clinical trials, study results, and other information pertinent to the treatment of MS and the care of individuals affected by the disease. MSAA publishes this information in a bimonthly online article series, “What’s New in MS Research,” and periodically in a biannual magazine, The Motivator. When disseminating breaking news, such as FDA approvals of new MS treatments, MSAA will publish an article on their website. All medical content is reviewed by MSAA’s chief medical officer.

In general, MSAA only publishes information from abstracts or articles that have been peer-reviewed and accepted for national/international medical conferences or by medical periodicals. MSAA also accepts press releases for informational purposes only; external press releases are not posted on MSAA’s website.

In terms of specific clinical trial listings, MSAA currently has a partnership with Antidote, a digital patient engagement company that helps people locate clinical trials that are appropriate for them. Antidote's clinical trial platform/search tool has been integrated into MSAA's website for the MS community to access pertinent clinical trial information.

RealTalk MS Podcast

https://realtalkms.com

Jon Strum (jonstrum@realtalkms.com | (310) 526-2283)

RealTalk MS is a weekly podcast that highlights advances in MS research and features interviews with MS researchers and other leaders in the MS community. MS researchers can share information and research results by contacting Jon Strum via email.

MS Foundation

www.msfocus.org

Kasey Minnis (kasey@msfocus.org | admin@msfocus.org)
Director of Operations and Communications
(800) 225-6495

The MS Foundation collaborates with researchers to disseminate information to the MS community. This information may include research results and study recruitment information for researchers in academic institutions/nonprofit agencies. Researchers should contact the communications department at editor@msfocus.org. Once the information has been presented, the editorial team decides which communication channels are most appropriate for sharing it. Typically, new research results are shared on the website's news section, research newsletter, and on social media. Select information may also be shared in the MS Foundation magazine.

Accelerated Cure Project

www.acceleratedcure.org
https://www.acceleratedcure.org/resources-mrepn/

ACP Newsletter: info@acceleratedcure.org
iConquerMS: info@iConquerMS.org

Accelerated Cure Project (ACP) is a non-profit organization dedicated to accelerating research efforts to improve diagnosis, to optimize treatment and to cure multiple sclerosis. ACP produces a monthly newsletter with feature stories about research topics and advances. ACP also sponsors iConquerMS, a research network for people affected with MS, and offers opportunities to disseminate research results on the iConquerMS website.

The ACP website also hosts an online repository of minority health and research resources. Please send a message to msminorityresearch@acceleratedcure.org to have your publication or other resource included there.

MS Living Well Podcast

https://www.mslivingwell.org/podcast/

Dr. Barry Singer
info@MSLivingWell.org | (314) 996-7773

Barry Singer, MD, Director of The MS Center for Innovations in Care at Missouri Baptist Medical Center, interviews global medical experts and patient advocates about the latest treatments, innovations, and tips for patients living with multiple sclerosis. Dr. Singer’s podcast episodes are topic-based and feature guests that include researchers with interesting new findings. He also has a blog on mslivingwell.org where he can disseminate important new results.

Brain Chat with the Nerdy Neurologist

https://joilifefoundation.com/brainchat-podcast/

Joi Life Wellness Group, LLC - Joi Life Foundation
Dr. Mitzi Joi Williams - Co-Founder, Chief Medical Officer | drmitzi@joilifewellness.com
Samira Taylor - Administrative Coordinator | samira@joilifewellness.com

Dr. Williams' podcast is topic-based and her guests and topics are scheduled 6 months in advance. Researchers are invited to contact Dr. Williams about appearing on an episode to share their new findings.

Real Lyfe Reel Talk

https://www.1027espn.com/show/real-lyfe-reel-talk-with-tyler-campbell

Tyler Campbell - Radio Host and MS Patient
https://iamtylercampbell.com | Tyler@TCSpeaks.com

Tyler Campbell is an MS advocate and inspirational speaker who hosts a weekly radio show, "Real Lyfe Reel Talk with Tyler Campbell."

MS Views and News

https://www.msviews.org/msviewsandnews4/

https://msviewsandnews.org/contact | (888) 871-1664

MS Views and News (MSVN) is a grassroots, non-profit patient advocacy organization which provides educational programs, advocacy and resources to empower and enhance the quality of life for the MS community. An important part of MSVN's mission is to provide MS educational information and resources to MS patients and care partners living in rural and underserved communities in the USA.

Additional Multilingual/Multicultural Dissemination Partners

- LACTRIMS (Latin American Committee for Treatment and Research in MS) - Spanish
  secretaria@lactrimsweb.org | General Projects Coordinator - Dr. Victor Rivera (vrivera@bcm.edu)
- MSAA (Hispanic/Latinx Initiatives) Spanish - Yahaira Rivera (yrivera@mymsaa.org)
- National MS Society - Spanish | Neisha Fredericks (neisha.fredericks@nmss.org)
- Fundación de Esclerosis Múltiple de Puerto Rico - Spanish
  Executive Director - Lourdes Fernández Trujillo (lourdes.fernandez@fempr.org, (787) 723-2331)
- MS International Federation - Multiple | https://www.msif.org/resources/

STUDY DISSEMINATION EXAMPLES

Following are examples of non-MS studies that have shared their results with the general public and/or specific underserved communities.

- **Pass It On Clinical Study** (English; Spanish)
    - Websites that provide clinical study results through infographics and videos
    - Also includes sections "From the Perspective of Participants"
- **Randomized Trial to Prevent Vascular Events in HIV (REPRIEVE) Participant Newsletter** (English)
    - Newsletter distributed as the study ended
    - Includes a closing message from the research team, study facts, participant interviews, and research findings
    - Available in multiple languages
- **Camino Research Institute - Latino Community Strength and Needs Assessment (LCSNA) One Page Findings Summary** (English & Spanish)
    - A clear, one page summary of results including demographics, strengths, and needs
    - Includes text and graphs/figures
- **Black Women's Health Study e-Newsletter** (BWHS Jan 2024)
    - Focused on Black/African American Women
    - Includes information about recent coverage in a Boston-based magazine, recent research results, information regarding new funding, report of recent meeting of their Community Advisory Board, and upcoming study tasks
    - Additional issues of the newsletter can be found here
- **Growing Up Today Study (GUTS) Participant Newsletters** (GUTS Newsletters)
    - Series of newsletters for the GUTS study (1997-2018)
    - Includes messages and updates from the research team, "Recent Findings," and an interview with a member of the study team
- **APHA How Climate Change Affects Your Health Infographics** (Infographics)
    - Series of infographics that are presented in separate sections and then combined to present a full "model"
- **Vanderbilt Institute for Clinical and Translational Research** (VICTR)
    - Provides guidelines, templates, and examples, like summaries, infographics, and videos
    - Does require that you fill out a REDCap form detailing your background and need to access some materials

CONCLUSION

Disseminating clinical study findings to underrepresented communities in MS research is essential for promoting equity and trust within the healthcare system. Sharing results fosters reciprocity, benefits future research, fulfills ethical obligations, and ensures accessibility for all. Despite potential barriers, strategies exist to overcome these challenges. By developing tailored dissemination plans, understanding target audiences, and employing appropriate communication formats, researchers can effectively share their findings with communities. Collaboration with advocacy groups and utilization of various communication channels are crucial for enhancing outreach efforts and ensuring dissemination materials are culturally sensitive and relevant. Overall, transparent and inclusive dissemination practices contribute to informed decision-making and empower individuals affected by MS.

This guidance document was developed by members of the MS Minority Research Engagement Partnership Network (MS MREPN), a multi-stakeholder collaborative network focused on identifying and addressing the barriers to participation in MS research. Network members include individuals living with MS, industry representatives, researchers, advocacy groups, healthcare providers, and other stakeholders. All are welcome to join this strategic and collaborative network.

For more information, including how to get involved with the MS MREPN, please visit our website at www.acceleratedcure.org/ms-mrepn/ or contact us at msminorityresearch@acceleratedcure.org.

REFERENCES

1. Mfutso-Bengo, J., Ndebele, P., & Masiye, F. (2008). Disseminating research results to research participants and their communities. Malawi medical journal : the journal of Medical Association of Malawi, 20(2), 64–66. https://doi.org/10.4314/mmj.v20i2.10959.
2. Cook, S., Mayers, S., Goggins, K., Schlundt, D., Bonnet, K., Williams, N., ... & Barkin, S. (2020). Assessing research participant preferences for receiving study results. Journal of Clinical and Translational Science, 4(3), 243-249. https://doi.org/10.1017/cts.2019.427.
3. Long, C. R., Stewart, M. K., Cunningham, T. V., Warmack, T. S., & McElfish, P. A. (2016). Health research participants' preferences for receiving research results. *Clinical trials (London, England)*, *13*(6), 582–591. https://doi.org/10.1177/1740774516665598.
4. McElfish, P. A., Long, C. R., James, L. P., Scott, A. J., Flood-Grady, E., Kimminau, K. S., Rhyne, R. L., Burge, M. R., & Purvis, R. S. (2019). Characterizing health researcher barriers to sharing results with study participants. *Journal of clinical and translational science*, *3*(6), 295–301. https://doi.org/10.1017/cts.2019.409.
5. McNeal, D. M., Glasgow, R. E., Brownson, R. C., Matlock, D. D., Peterson, P. N., Daugherty, S. L., & Knoepke, C. E. (2020). Perspectives of scientists on disseminating research findings to non-research audiences. *Journal of clinical and translational science*, *5*(1), e61. https://doi.org/10.1017/cts.2020.563
6. Sgro, G. M., Maurer, M., Nguyen, B., & Siegel, J. E. (2023). Return of aggregate results to study participants: Facilitators, barriers, and recommendations. *Contemporary clinical trials communications*, *33*, 101136. https://doi.org/10.1016/j.conctc.2023.101136.
7. Schroter, S., Price, A., Malički, M., Richards, T., & Clarke, M. (2019). Frequency and format of clinical trial results dissemination to patients: a survey of authors of trials indexed in PubMed. BMJ open, 9(10), e032701. https://doi.org/10.1136/bmjopen-2019-032701.
8. Rivkin, I., Trimble, J., Lopez, E. D., Johnson, S., Orr, E., & Allen, J. (2013). Disseminating research in rural Yup'ik communities: challenges and ethical considerations in moving from discovery to intervention development. *International journal of circumpolar health*, *72*, 10.3402/ijch.v72i0.20958. https://doi.org/10.3402/ijch.v72i0.20958.
9. Buchanan, N. T., Perez, M., Prinstein, M. J., & Thurston, I. B. (2021). Upending racism in psychological science: Strategies to change how science is conducted, reported, reviewed, and disseminated. *The American psychologist*, *76*(7), 1097–1112. https://doi.org/10.1037/amp0000905.
10. Bodison, S. C., Sankaré, I., Anaya, H., Booker-Vaughns, J., Miller, A., Williams, P., Norris, K., & Community Engagement Workgroup (2015). Engaging the Community in the Dissemination, Implementation, and Improvement of Health-Related Research. Clinical and translational science, 8(6), 814–819. https://doi.org/10.1111/cts.12342.
11. Hood, A. M., Booker, S. Q., Morais, C. A., Goodin, B. R., Letzen, J. E., Campbell, L. C., Merriwether, E. N., Aroke, E. N., Campbell, C. M., Mathur, V. A., & Janevic, M. R. (2022). Confronting Racism in All Forms of Pain Research: A Shared Commitment for Engagement, Diversity, and Dissemination. *The journal of pain*, *23*(6), 913–928. https://doi.org/10.1016/j.jpain.2022.01.008.
12. Long, C. R., Purvis, R. S., Flood-Grady, E., Kimminau, K. S., Rhyne, R. L., Burge, M. R., Stewart, M. K., Jenkins, A. J., James, L. P., & McElfish, P. A. (2019). Health researchers' experiences, perceptions and barriers related to sharing study results with participants. *Health research policy and systems*, *17*(1), 25. https://doi.org/10.1186/s12961-019-0422-5.
13. Walde, P., & Völlm, B. A. (2023). The TRAPD approach as a method for questionnaire translation. Frontiers in Psychiatry, 14, 1199989. https://doi.org/10.3389/fpsyt.2023.1199989.

14. The FACIT Group. https://www.facit.org.
15. Melvin, C. L., Harvey, J., Pittman, T., Gentilin, S., Burshell, D., & Kelechi, T. (2020). Communicating and disseminating research findings to study participants: Formative assessment of participant and researcher expectations and preferences. Journal of clinical and translational science, 4(3), 233-242. https://doi.org/10.1017/cts.2020.9.
16. Cunningham-Erves, J., Mayo-Gamble, T., Vaughn, Y., Hawk, J., Helms, M., Barajas, C., & Joosten, Y. (2020). Engagement of community stakeholders to develop a framework to guide research dissemination to communities. Health expectations : an international journal of public participation in health care and health policy, 23(4), 958–968. https://doi.org/10.1111/hex.13076.
17. Heerman, W. J., Wilkins, C. H., & Barkin, S. L. (2021). Disseminating aggregate research findings to participants. Pediatric research, 89(4), 714-715. https://doi.org/10.1038/s41390-020-0995-2.

ADDITIONAL REFERENCES

1. Brownson, R. C., Eyler, A. A., Harris, J. K., Moore, J. B., & Tabak, R. G. (2018). Getting the Word Out: New Approaches for Disseminating Public Health Science. *Journal of public health management and practice* : *JPHMP*, *24*(2), 102–111. https://doi.org/10.1097/PHH.0000000000000673.
2. Chapman, E., Haby, M. M., Toma, T. S., de Bortoli, M. C., Illanes, E., Oliveros, M. J., & Barreto, J. O. M. (2020). Knowledge translation strategies for dissemination with a focus on healthcare recipients: an overview of systematic reviews. Implementation science : IS, 15(1), 14. https://doi.org/10.1186/s13012-020-0974-3.
3. Communication and Dissemination Strategies To Facilitate the Use of Health-Related Evidence - https://effectivehealthcare.ahrq.gov/products/medical-evidence-communication/research-protocol.
4. Crosswaite, Catriona & Curtice, Lisa (1994). Disseminating research results-the challenge of bridging the gap between health research and health action, Health Promotion International, 9(4), 289–296. https://doi.org/10.1093/heapro/9.4.289.
5. Cunningham-Erves, J., Stewart, E. C., Duke, J., Alexander, L., Davis, J., Wilus, D., Wyche-Etheridge, K., & Miller, S. T. (2022). Use of Community Listening Sessions to Disseminate Research Findings to Past Participants and Communities. Journal of community health, 47(2), 201–210. https://doi.org/10.1007/s10900-021-01038-4.
6. Cunningham-Erves, J., Stewart, E., Duke, J., Akohoue, S. A., Rowen, N., Lee, O., & Miller, S. T. (2021). Training researchers in dissemination of study results to research participants and communities. Translational behavioral medicine, 11(7), 1411–1419. https://doi.org/10.1093/tbm/ibab023.
7. Derman, R.J., Jaeger, F.J. Overcoming challenges to dissemination and implementation of research findings in under-resourced countries. Reprod Health 15 (Suppl 1), 86 (2018). https://doi.org/10.1186/s12978-018-0538-z.
8. Glasgow, R. E., Vinson, C., Chambers, D., Khoury, M. J., Kaplan, R. M., & Hunter, C. (2012). National Institutes of Health approaches to dissemination and implementation science: current and future directions. American journal of public health, 102(7), 1274–1281. https://doi.org/10.2105/AJPH.2012.300755.
9. Marín-González, E., Malmusi, D., Camprubí, L., & Borrell, C. (2017). The Role of Dissemination as a Fundamental Part of a Research Project. *International journal of health services : planning, administration, evaluation*, *47*(2), 258–276. https://doi.org/10.1177/0020731416676227.

10. Pufall, E. L., Jones, A. Q., McEwen, S. A., Lyall, C., Peregrine, A. S., & Edge, V. L. (2011). Community-derived research dissemination strategies in an Inuit community. *International journal of circumpolar health*, *70*(5), 532–541. https://doi.org/10.3402/ijch.v70i5.17860.
11. Schroter, S., Price, A., Malički, M., Richards, T., & Clarke, M. (2019). Frequency and format of clinical trial results dissemination to patients: a survey of authors of trials indexed in PubMed. BMJ open, 9(10), e032701. https://doi.org/10.1136/bmjopen-2019-032701.
12. Wilson, P. M., Petticrew, M., Calnan, M. W., & Nazareth, I. (2010). Disseminating research findings: what should researchers do? A systematic scoping review of conceptual frameworks. Implementation science : IS, 5, 91. https://doi.org/10.1186/1748-5908-5-91.

ADDITIONAL HELPFUL LINKS

- Everyday Words for Public Health Communication
- https://www.ruralhealthinfo.org/toolkits/rural-toolkit/6/dissemination-methods
- https://med.stanford.edu/content/dam/sm/ourvoice/documents/Dissemination%20Research.pdf
- https://prevention.ucsf.edu/sites/prevention.ucsf.edu/files/uploads/projects/collaboration/pdf/CABDisseminationGuidelines.pdf
- https://www.urban.org/sites/default/files/publication/104938/tools-and-resources-for-project-based-community-advisory-boards_0.pdf

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