



MSKTC
SCI • TBI • BURN

Model Systems
Knowledge Translation
Center

Engaging With Audiences: A Learning Collaborative

Sharing Model Systems Activities and Innovations To Engage Stakeholders

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INTRODUCTION

On May 28, 2013, the Model Systems Knowledge Translation Center (MSKTC), funded by the National Institute on Disability and Rehabilitation Research (NIDRR), held a webinar titled *Engaging With Audiences: A Learning Collaborative*. (The recorded webinar is available online at <http://www.msktc.org> under the “For Grantees” tab.) The webinar included presentations from several NIDRR-funded Model Systems (MS) grantees who conduct research in the areas of spinal cord injury (SCI), traumatic brain injury (TBI), and burn injury (Burn), as well as information shared by the American Institutes for Research (AIR) on measuring stakeholder engagement. This compendium provides examples of how some MS researchers engage stakeholders throughout the research process, which other researchers may consider as they work toward greater stakeholder engagement in their studies. (The terms *stakeholder* and *audience* are used interchangeably in this presentation.)

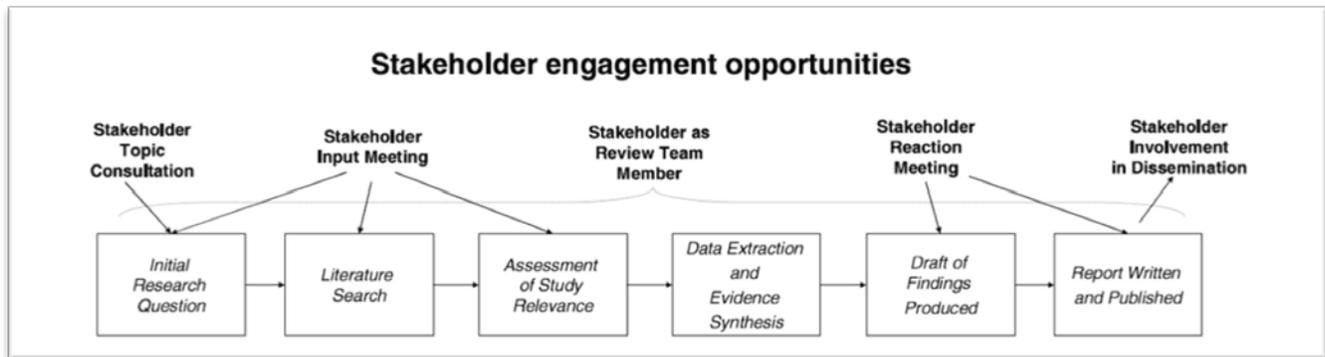
The MS grantees conduct research that engages audiences including patients, their family members and other caregivers, clinicians, policymakers, and other researchers. The value and methods of engaging various types of audiences were highlighted through the examples shared by the MS grantees. Because stakeholder engagement is threaded throughout much of the work that the MS grantees conduct, it is important to measure the outcomes of engagement itself. The *Engaging With Audiences* webinar discussed ways in which this engagement could be measured and offered sample questionnaire items.

Stakeholder Engagement Model

Exhibit 1 presents a model of stakeholder engagement¹ that offers a visual representation of the general research process and how stakeholders are engaged along the way. There are opportunities to engage stakeholders—particularly patients and their caregivers—throughout the research process. For example, stakeholders may be involved in helping to select or refine the research question or approach. They may provide input about the relevance of a planned study to their lives and work. Also, there is great value in asking patients or clinicians to look through data, because they may identify different kinds of conclusions than the researcher. Sometimes stakeholders are engaged in the conduct of research and data analyses, as well as the publications that results—whether co-authoring a report or helping to review it for plain language. Stakeholders can also be a tremendous help in disseminating research findings or products.

¹ Keown, K., Van, E. D., & Irvin, E. (2008). Stakeholder engagement opportunities in systematic reviews: Knowledge transfer for policy and practice. *Journal of Continuing Education in the Health Professions*, 28, 67–72.

Exhibit 1. Stakeholder Engagement Opportunities



About the Compendium

Given the value of stakeholder engagement in the research process, MSKTC contacted several SCI, TBI, and Burn researchers to share examples of how they are engaging stakeholders throughout this process. These examples informed the webinar held on May 28, 2013, and are explained in greater detail in the following pages to highlight the importance of engaging audiences throughout the research process and the value of those audiences to inform MS research.

Brief bios of the MS researchers who presented their work at the webinar are presented in Appendix A and on the MSKTC Web site (<http://www.msktc.org>).

BUILDING TRUST WITH PATIENTS: WORKING WITH BURN SURVIVORS

Radha Holavanahalli), Ph.D.,

(<http://www.msktc.org/researchcenter/detail/TexasBurn/Radha-Holavanahalli>)

Research Director

North Texas Burn Rehabilitation Model System

The Initial Research Question: Setting the Goal

(Stakeholder Topic Consultation)

The North Texas Burn Rehabilitation Model System (NTBRMS) has focused on building relationships and trust with burn injury patients by working together with local support groups—the Phoenix Society for Burn Survivors, and Changing Faces, a charity organization based in the United Kingdom that helps individuals affected by facial disfigurement. This engagement has helped to build trust between burn survivors and the researchers.

“They saw that we are not just a group of researchers with data folders getting information and forgetting about them,” says Research Director Dr. Holavanahalli.

The research team engaged consumers in surveys to determine the relevance of research topics to burn survivors and their families and also created a peer-support training opportunity that involves burn survivors. Several burn injury patients also serve on the advisory board of the MS to provide feedback on research and activities.

Who Is Involved?

(Stakeholder as Review Team Member)

NTBRMS invited James Partridge from Changing Faces to speak to physical medicine and rehabilitation residents, therapists, and therapy students at the MS Grand Rounds. The burn survivors also were invited to attend, and the feedback received from them stressed upon the importance of social skills training for community re-entry. As a result, NTBRMS decided to use the 3-2-1-Go program developed by Changing Faces, and proposed a research study to test the effectiveness of this intervention.

Similar feedback was received when Barbara Kammerer-Quayle from the Phoenix Society was invited to the BMS to provide Behavior Enhancement Skills Training. The BMS researchers collaborated with the Phoenix Society in its plan to develop a web-based adaptation of this social skills training program. The evaluation of the web-based program is part of the NTBRMS research agenda.

In addition, current burn injury patients and returning burn survivors are engaged in the BMS advisory board, review and selection of research topics, and peer-support training.

What Are Stakeholders Doing?

(Stakeholder Input)

Researchers provide support group members (i.e., burn survivors) with a list of potential study topics and ask survivors to provide input and feedback on the relevance, usefulness, and applicability of those topics. In some instances, survivors offer new topics that they feel represent common issues that should be considered. As a result, the MS researchers have been able to pinpoint the more pressing issues—such as social skills, community re-entry, and heat sensitivity—for individuals with burn injuries.

In addition, the researchers have asked members of this active support group to identify other patients and family members who would like to serve as peer-support volunteers. After selecting peer-support volunteers who meet certain criteria (e.g., not recently discharged) and who are screened by a psychologist, the researchers conduct standardized peer-support training using the Phoenix Society program, “Survivors Offering Assistance in Recovery” (SOAR). This program covers a variety of topics, such as how to work in a hospital setting, the role of the peer supporter, boundaries, do’s and don’ts, communication skills, and the process of psychosocial recovery for patients and families. Dr. Radha Holavanahalli, Research Director for NTBRMS, is a certified peer-support instructor and is currently undertaking that role. Importantly, Dr. Holavanahalli is actively engaged in activities that help illuminate a different perspective—she can look at the issue through a researcher lens and as someone who has direct experience with burn survivors. The MS has trained SOAR coordinators (e.g., physical therapists, occupational therapists, nurses, and research assistants) to facilitate the face-to-face peer visits in the burn unit.

Also, the MS has used the help of burn survivors to produce a 10-minute video titled, *In Their Own Words . . .* The video captures difficult situations that burn survivors deal with every day and how they overcame those challenges. The video was presented at the Aftercare and Reintegration Committee (ARC) forum at the American Burn Association annual conferences in 2010 and 2012, and can also be found online: <http://www4.utsouthwestern.edu/video/burn2010.html>

How Will the Effectiveness of the Intervention Be Measured?

(Stakeholder Reaction)

In addition to looking at ways to potentially measure the outcomes of engaging with burn survivors through the programs noted above, research team is studying the effectiveness of the Phoenix Society’s online program and the Changing Faces 3-2-1-Go program. The 3-2-1-Go program is used in an intervention study that is ongoing. Subjects are randomly assigned to a training group that receives social skills training and a control group that does not receive the training. Both groups are tested for social interaction anxiety. The Phoenix Society’s online social skills program is part of the MS’ site-specific project for the current funding cycle (2012–2017). The goal of this study is test knowledge, practice, and health outcomes. Additionally, researchers use the input and feedback on possible

research topics provided by survivors and their family members as affirmation that they're moving in the right direction in terms of research.

Also, NTBRMS publishes a quarterly newsletter and consistently invites burn survivors to contribute by submitting discussions of their experiences, recovery processes, and success stories. Surveys are conducted with the patients who read the newsletter to find out what portions are most useful; patients usually respond that they really enjoy the success stories. Realizing that researchers are willing to sit and talk with them, learn what information actually helps them, and then include that information in a way that's useful helps to build trust between the patients and the researchers.

What Are the Dissemination Plans?

(Stakeholder Involvement with Dissemination)

NTBRMS would like to continue to engage burn patients in disseminating information to other consumers. The value of having someone who has survived a burn injury to share information is much more powerful than offering information from even the most empathetic researcher or clinician.

NTBRMS engages burn survivors in BMS dissemination plans in various ways:

- **Publishes findings in newsletters.** Burn survivors and their family members can use this information during support group discussions and peer-support visits and interactions. The BMS periodically sends out a survey to solicit feedback regarding the utility of newsletters.
- **Develops fact sheets in collaboration with the MSKTC.** Fact sheets provide usable information to burn survivors, which they can use in ways similar to that of newsletters. Recently, some burn survivors (who serve on the Burn Survivor Advisory Board) provided feedback on a fact sheet that was produced by the BMS.
- **Solicits input from members of the Burn Survivor Advisory Board.** The input pertains to mechanisms for effective access, delivery, and utilization.
- **Publishes research findings.** The BMS has published research findings in the Phoenix Society's *Burn Support News*. Burn survivors make up a very large portion of the readership.
- **Encourages participation in an education panel.** Burn survivors are also invited to participate in an education panel for nursing students' burn education and training program.

Challenges and Solutions

Getting useful information to consumers. Consumers may be frustrated that burn centers do not always have the type of information that they are looking for. Relevant and interesting materials produced by the Phoenix Society are not always distributed by professionals in burn centers because the products are not validated by research. *Survivors don't always want to wait for research to be conducted on*

*Notes Dr. Holavanahalli,
"What [burn survivors] want
to know is, 'what will help
me?'"*

the information they need now (such as social skills or community re-entry). NTBRMS team is working to build that bridge.

Connecting with hard-to-reach consumers. Some survivors who live in isolation (many of whom are at least a decade post-injury) are not exposed to any of the burn resources that are available. It is difficult to determine what issues impact them and the kind of information or resources that will be helpful to them.

Long-term outcomes of major burn injuries, aging with burns, and similar topics. NTBRMS would like to lead focus groups with this population to hear their concerns, learn how they are dealing with their injury years later, and learn about long-term outcomes.

ENGAGING PATIENTS, FAMILIES, AND CLINICIANS IN TBI RESEARCH

Tessa Hart, Ph.D., Principal Investigator

Moss Rehabilitation Research Institute Traumatic Brain Injury Model System

The Initial Research Question: Setting the Goal

(Stakeholder Topic Consultation)

When designing a study, researchers at the Moss Rehabilitation Research Institute (MRRI) conduct focus groups with stakeholders to learn answers to the following types of questions:

- What topics are important to consumers?
- What is important about a given topic?
- What would consumers like to see addressed in this topic area?
- Do consumers think that a proposed topic is feasible and what are potential barriers to success?

The research team also surveys stakeholders to learn which general topics are of interest.

Who Is Involved?

(Stakeholder Input Meeting)

The MRRI TBIMS has different stages of research development in which to engage patients with traumatic brain injury. Because of challenges to identify individuals, form a group, and bring them together, the research team connects with an existing group of patients who meets regularly e.g., a brain injury support group that meets at the center or a clinical group meeting as part of the outpatient program. Researchers may request an opportunity to talk with the group members about topics that are important to them.

These discussions begin by sharing the research and ideas on which the TBI MS has been working, and then proceed by asking the consumers what else the researchers should look at. This keeps the researchers in touch with what's important to individuals with a brain injury.

What Are Stakeholders Doing?

(Stakeholder Review Team Member; Stakeholder Reaction)

Sometimes the research team has a specific topic in mind and asks pointed questions about specific research proposals or activities. For example, when the MRRI team was developing a project about using text messages, it wanted to learn whether people with TBI use messaging, in what way, and what barriers they faced. The MRRI team learned the proportion of people who use text messaging and that many more would like to do so but cannot afford a phone. Thus, the cost of a phone can be a barrier to

a patient's use of text messaging. The team also learned that older people in the general population and in the center's TBI population do less texting than younger people; the older people are intimidated. As a result, the researchers stipulated in their project that if participants did not already use text messaging with a cell phone, the researchers would design a training program to show participants how to do it and provide a pay-as-you-go phone if needed. The stakeholder input helped the team to design a project to help people who were not already using technology to do so.

The MRRI TBI MS works with consumers of information (patients, caregivers, clinicians) in a variety of other ways to gather input, review materials, and gain insight.

- **Focus groups.** The team conducted focus groups with family members and nurses for an inpatient project on pain measures. Families confirmed that this was an important topic to study, as they could see that the patients were in pain but the patients were not always able to voice this or identify what exactly was the matter. These families shared that the project topic was important, and encouraged the team to continue research on the topic. The nurses gave input to the scale items that were included; family members also gave input to those items by suggesting how to refine them or adding new ideas for items.
- **Pilot studies.** Through pilot studies and discussion groups with clinicians, the research team reviewed the Moss Attention Rating Scale² (MARS), an observational rating scale created by Dr. Hart and her colleagues at MRRI as well as other Model Systems researchers. The research team asked clinicians to review the scale to assist the team in creating an, later, weeding out items. Clinicians are ultimate users of MARS, so their input was substantial. In addition, at professional conferences, the researchers distributed questionnaires to clinicians outside their institution to learn about the likelihood that other clinicians would use MARS, and to learn whether they found the tool helpful.
- **Interviews.** Recently, the research team conducted an interview with a patient with TBI to walk through a manual created as an intervention for depression and anxiety. The patient provided feedback on whether the information made sense, the wording was clear, the right information was emphasized—a tremendous amount of the manual was revised due to his input. It was also helpful to have male input to this issue of depression and anxiety to make sure the language works for men as well as women.
- **Questionnaires.** The research team also piloted a questionnaire to measure outpatient services via self-reports, to make sure that patients understood the questions about the type and quantity of outpatient services received. Based on input from patients, the questionnaire was reworded to make the questions clearer.

What Are the Dissemination Plans?

(Stakeholder Involvement with Dissemination)

² Hart, T. (2008). The Moss Attention Rating Scale. *The Center for Outcome Measurement in Brain Injury*. <http://www.tbims.org/combi/mars> (accessed July 5, 2013).

MRRRI conducts a 1-day conference during each TBI MS cycle to provide education and networking opportunities for people with brain injury and family members. A full year is devoted to planning this conference so that consumers can be included as fully as possible. Consumer input is responsible for identifying topics. Most workshops are planned and conducted by clinicians and consumers teaching side-by-side. MRRRI also facilitates seminars for consumers in rural parts of Pennsylvania and have developed a toolkit to help consumer groups plan and run their own seminars on a regular basis.

Challenges and Solutions

As noted above, it has been challenging to identify individuals with TBI to form a group; however, we have engaged them through existing patient support groups. We have found patients and caregivers are interested in sharing their ideas and opinions with us. In addition, there are challenges to engaging clinicians due to time constraints and encouraging them to systematically use research findings in their work; however, we have not faced barriers to engaging them in our research. They are motivated to participate in the research and development of tools that we conduct.

MY CARE, MY CALL: SCI STAKEHOLDER ENGAGEMENT

Bethlyn Houlihan, M.S.W., M.P.H.

<http://www.msktc.org/researchcenter/detail/NewEnglandSCI/Bethlyn-Houlihan>

New England Regional Spinal Cord Injury Center Network

The Initial Research Question: Setting the Goal

(Stakeholder Topic Consultation)

My Care, My Call is a novel intervention designed by the New England Regional Spinal Cord Injury Center Network (NERSCIC), in which Bethlyn Houlihan is engaging stakeholders in the process of developing automated phone training for people with SCI to self-advocate in the primary care physician's office. To begin, NERSCIC staff interviewed stakeholders to determine whether this was an appropriate approach to address a high area of need.

Who Is Involved?

(Stakeholder as Review Team Member)

To ensure that My Care, My Call addressed the needs of consumers, the team at NERSCIC created a content expert panel with stakeholders that included some of those individuals who had vetted the project idea. This included people with SCI, those from minority backgrounds, a member of United Spinal/the National SCI Association (US/NSCIA), a long-term case manager, a physical therapist, a social worker, and a program director of a State rehabilitation commission. Members will receive a small stipend. NERSCIC also hired a part-time consultant who has an SCI to be part of the panel and to be the self-advocacy coach for the randomized controlled trial (RCT) of My Care, My Call.

What Are They Doing?

(Stakeholder Input; Stakeholder Reaction)

Before developing scripts for the training, the panel conceptualized the flow of the intervention, addressed major themes, and discussed other critical considerations. The research team is now actively developing script content, and asking the expert panel to review and provide feedback in a "live test" format over the phone where they assume the identity of a mock system user, and a research team member follows script content to interact as the computer phone system would.

The research team will pilot the training with consumers before it is finalized. The team will select eight individuals from various profiles [e.g., those who adhered and did not adhere to a previous related project (Care Call), newly injured and chronic patients, and so forth] to give feedback on the system through semistructured qualitative interviews after each call. Results will inform final revisions to the system.

How Will the Effectiveness of the Intervention Be Measured?

(Stakeholder Reaction)

RCT with 60 subjects (30 intervention, 30 usual care):

- **Hypothesis #1.** Compared with those receiving usual care, participants in the My Care, My Call telehealth module will increase their self-advocacy in health care interactions with their primary care physicians as reflected in increases in three domains: self-advocacy: assertiveness, illness education, and potential for mindful non-adherence.
- **Hypothesis #2.** Compared with those receiving usual care, the My Care, My Call intervention will increase users' self-efficacy for health care navigation and preference for involvement in and satisfaction with their primary care physician.

NERSCIC will conduct a series of process analyses from the RCT to examine use of and satisfaction with My Care, My Call, and whether use is associated with study outcomes. NERSCIC will describe the number and pattern of calls that reached participants, the number of calls completed by participants, and average ratings by users. NERSCIC will examine user characteristics (e.g., age, sex, race/ethnicity, education) as predictors of use of the system. NERSCIC will also conduct a dose-response analysis to examine potential associations between level of use and study outcomes. Lastly, NERSCIC will examine data from exit interviews on satisfaction with My Care, My Call. These analyses may provide insights into maximizing the potential benefit of this approach for consumers.

What Are the Dissemination Plans?

(Stakeholder Involvement with Dissemination)

The expert panel will actively participate in presentations to community groups and at conferences, publish consumer articles (e.g., Mobility magazine), vet consumer-focused materials (e.g., fact sheets and MSTKC quick reviews), disseminate findings to their networks, and promote the intervention if efficacious. The team is also working to package My Care, My Call as a product for members of US/NSCIA, which includes other hospitals, chapters around the country, and support groups.

Challenges and Solutions

A challenge for the team has been finding a way to engage the panel meaningfully in light of their limited time and availability. The research team has learned that with each task presented to panel members, it is particularly important to strategize ahead of time to keep the goal of the task and their role focused yet meaningful, and to honor the amount of time estimated it will take. Panel members requested a panel task timeline chart, which they reported can help them to conceptualize the flow of the project and their role throughout. In addition, follow-up calls to gather feedback can be time consuming, so the team has worked carefully to set clear limits on additional discussions during calls so that calls can be kept focused and brief.

Lastly, several panel members do not quite understand some of the underlying premises of the intervention. Together, the research team brainstormed how to approach this. Through individual conversations with these panel members, the project director created a new project task that better utilizes their strengths and maximizes their contributions while limiting their frustrations. The team learned how to be match tasks to the talents of various stakeholders through conversation with them.

PARTICIPATORY ENGAGEMENT IN WHEELCHAIR DESIGN FOR SCI USERS

Michael L. Boninger, M.D., (<http://www.msktc.org/researchcenter/detail/PittSCI/Michael-Boninger>), Director
University of Pittsburgh Model Center on Spinal Cord Injury

Annmarie Kelleher, M.S., (<http://www.herl.pitt.edu/person/annmarie-kelleher>) Lead Clinical Coordinator
Human Engineering Research Laboratories, University of Pittsburgh Model Center on Spinal Cord Injury

The Initial Research Question: Setting the Goal

(Stakeholder Topic Consultation)

Through a participatory design format, the University of Pittsburgh Model Center on Spinal Cord Injury (UPMC-SCI) team conducts research using focus groups and questionnaires to get user input on engineering tasks, designs, and development for wheelchairs. The team includes researchers, data collectors, rehabilitation counselors, a psychologist, and graduate students who are also individuals with SCI. Currently, the team is conducting approximately half-a-dozen studies using focus groups to get feedback on design options.

As Michael Boninger, director of UPMC-SCI, notes, “There are short- and long-term methods of engagement. Short-term includes focus groups, advisory boards, and participatory research. Long-term is actively and dynamically getting more people with disabilities involved in the STEM (science, technology, engineering, and mathematics) area of study. . . . The more we have people engaged in the process because of their STEM, technology, and medical background, the more long-term and involved it becomes.”

Who Is Involved?

(Stakeholder as Review Team Member)

Participants are recruited from annual events the researcher team attends nationally, such as the National Veterans Wheelchair Games and Winter Sports Clinic, as well as numerous local events and expos. Depending on the project, the research team will involve both end-users (people with SCI) and clinicians, either in combination or separate focus groups. The choice of stakeholders and how to engage them depends on the stage of development of the research project.

The research team developed several research registries to help them identify people who use the type of technology they are developing. These registries were established as early as 2002 to maintain contact with former participants and to list potential users who may provide feedback about specific topics or projects. The registries are compliant with privacy regulations, and enrollees are contacted regularly to update information, share research results, and receive quarterly newsletters. Recipients are encouraged to provide feedback about projects highlighted in the newsletter.

What Are Stakeholders Doing?

(Stakeholder Input; Stakeholder Reaction)

End-users and other stakeholders are engaged at each phase of the research process. Research focuses on the needs of consumers through interviews, focus groups, and product feedback consultations. A multidisciplinary team of physicians, engineers, physical and occupational therapists, and researchers benefit from learning about the challenges that end-users face firsthand. Usually, the research team has an early prototype and description of the design. Feedback from end-users is sought at this stage through interviews or focus groups (e.g., how would a person with SCI use this product, would the person use it). Such feedback helps the research team to know whether it is on the right track.

Then, the team conducts a focus group with approximately 8–10 end-users that meet certain criteria and would benefit from the technology being developed. Participants can use the technology or tool, try it, or visualize it; the research team asks a series of questions to tease out what end-users like or dislike about the product. Standardized questionnaires are used to obtain objective information and subjective comments. Then, the team can consider and reflect on comments of members of the focus group.

In the next phase of the study, researchers often conduct a more in-depth evaluation, such as biomechanics testing. In-lab testing ensures that devices are useful in a structured environment, and in-home testing ensures that devices are functional and useful in a real-world environment. Individuals with SCI take home the device, use it for a few weeks, and then return to lab to provide feedback through questionnaires and/or one-on-one interviews.

How Will the Effectiveness of the Intervention Be Measured?

(Stakeholder Reaction)

Feedback throughout the phases of design and development from the wheelchair user helps to improve the effectiveness of the technology. Depending on the objectives of each research study, researchers will measure and consider feedback and input—obtained through, for example, standardized questionnaires, clinical or research assessment tools, and interviews—to guide further stages of development. Measures often get more general as the intervention moves along the design process. For example, increased participation is the ultimate goal of many of the technologies. Therefore participation and quality of life metrics end up being the most important outcome metrics deployed.

What Are the Dissemination Plans?

(Stakeholder Involvement With Dissemination)

The next step after completing a product is dissemination. In addition to peer reviewed research journals and publications, the research team makes every effort to distribute lay abstracts and articles to consumer-oriented publications, such as *Paraplegia News*. The research team, led by Dr. Boninger, has been instrumental in developing several consumer-oriented clinical practice guidelines for Paralyzed Veterans of America and MSKTC. The research team also disseminates information about

research results to more than 2,000 newsletter recipients and registry participants. In addition, researchers give presentations about the research at events held by local disability organizations and support groups.

Challenges and Solutions

A challenge for the team has been coordinating routine logistic issues. Individuals with disabilities tend to have issues with transportation or may need caregivers to assist them. The research team needs to be dynamic in reaching out to individuals with SCI given the advances in social media, although for this to be a viable method, researchers will need to know if people are actually using social media.

PARTICIPATORY ADVISORY COUNCIL: TBI STAKEHOLDER ENGAGEMENT

John Corrigan, Ph.D., (<http://www.msktc.org/researchcenter/detail/OhioTBI/John-Corrigan>)
Principal Investigator
Ohio Regional TBI MS; Director, Ohio Valley Center for Brain Injury Prevention and Rehabilitation

Jennifer Bogner, Ph.D., (<http://www.msktc.org/researchcenter/detail/OhioTBI/Jennifer-Bogner>)
Co-Principal Investigator
Ohio Regional TBI MS; Research Director, Ohio Valley Center for Brain Injury Prevention and Rehabilitation

The Initial Research Question: Setting the Goal

(Stakeholder Topic Consultation)

The Ohio State University (OSU) TBI MS established its first advisory committee 20 years ago. When the TBI Center at OSU was first funded by the U.S. Rehabilitation Services Administration, the center was part of a multi-State grant that served Indiana, Ohio, Virginia, and West Virginia. After the 5-year grant ended and the center became a TBI MS, the advisory committee continued to meet in a multi-State council (and have since added Michigan). Currently, the group meets twice annually in Columbus, Ohio, and communicates by phone calls and listservs between meetings.

Who Is Involved?

(Stakeholder as Review Team Member)

The advisory committee includes primary and secondary consumers (i.e., persons with TBI and their family members), as well as advocates, State brain injury association representatives, clinicians, and policymakers. The policymakers are those from State government agencies with an interest in or a legislative requirement to focus on TBI. Indiana, Michigan, Ohio, Virginia, and West Virginia are represented, although the individuals may change over time. Currently, six members have been involved in the advisory committee since the beginning 20 years ago, and the group varies from 25 to 35 members in a given year.

*According to John Corrigan,
Director of the OSU TBI MS,
“It is a fantastic group of
people. I cannot imagine doing
this research without them.”*

What Are Stakeholders Doing?

(Stakeholder Input; Stakeholder Reaction)

The OSU TBI MS advisory council engages in participatory action through activities from concept development to proposal review, where members help with refinement, implementation, and interpretation. Every 5 years, the advisory committee conducts an “envisioning process,” which involves

creating the vision and a strategic plan that aligns with that vision. The process takes 18 months to complete, and a part of each meeting is given to the process. To create the vision and strategic plan, the advisory committee looks at the world of brain injury research and activities. Strategic planning work begins with an environmental scan and the opportunity to hear from and talk with invited speakers, panels, and other groups. Then, the advisory committee refines the plan and identifies and prioritizes the major issues facing the field. Next, the TBI MS Center reflects back on the scan of the field and provides its thinking on how the Ohio Valley Center (OVC) can be effective in research and program development. During the past 20 years, there have been different areas of focus; two of those have persisted this entire time: substance abuse and long-term outcomes (currently TBI as a chronic health condition). Other focuses over the years have included the military, use of new technologies, and others. Essentially, this process gives the TBI MS Center and staff a big picture view of the kinds of grants they will search and apply for—the advisory committee gives them direction on where to look with the strategic plan as a guide.

The advisory committee realizes that the Center is not a business that can quickly adjust each year. Rather, the TBIMS must respond to what is available and what is changing including funding opportunities.

The advisory committee meetings also focus on the work of the Center, which presents progress reports on grants. The advisory subcommittees also provide reports. In their most recent meeting, for example, the advisory committee provided input on a plan for doing knowledge translation (KT) with caregivers using statewide systems. The advisory committee discussed information and resource supports, then helped to prioritize them. The next day, the Brain Injury Association of American provided progress reports, and then members shared “news from home,” as members of each State described the latest brain injury efforts in their respective communities.

What Is a Brain Injury Advisory Committee (BIAC)?

Most states have a brain injury advisory committee supported by grants from HRSA. There are four core conditions for establishing a brain injury advisory committee: (1) a designee in the State to lead planning and policy, (2) an advisory council made up of policymakers and other stakeholders, (3) a completed needs assessment, and (4) a completed action plan. The policymakers are State agency staff, not elected officials. In Ohio, the BIAC consists of eight directors of state departments or designees, a representative of the brain injury association, four or five consumers (primary and secondary), and others, as noted in the state’s legal statute. The BIAC meets every 2 months in Columbus, at the office of the lead agency, which must hire a full-time staff person. The Ohio BIAC is currently housed at the Ohio Rehabilitation Services Commission; however, in 2013, the BIAC may be moved to OSU, where John Corrigan would be responsible for leading this committee.

What Are the Dissemination Plans?

(Stakeholder Involvement with Dissemination)

One way in which the Ohio Valley Center disseminates findings from its studies is via State and national conferences. Advisory committee members who sponsor conferences frequently invite the center to speak (which is performed free of charge in participating States). The Ohio Valley Center has also been invited by the Brain Injury Association of America to do webinars (e.g., on substance abuse).

The Ohio Valley Center also provides synopses of two published works to the Brain Injury Association of America for its Web site and/or *The Challenge*. The Research Committee of the advisory committee reviews these synopses for consumer friendliness in advance of submission.

Challenges and Solutions

When the advisory committee was first formed, most participants wanted to “tell their story” including the consumers, clinicians, and State agency representatives. This required that we give time to participants to share their stories and develop a shared purpose before they could begin moving work forward. The advisory committee also met three or four times per year, more frequently than now. The advisory committee is written into grants, which provides the funding for this effort, so as funding shifts, so too does the number of in-person meetings.

Maintaining engagement with the AC has required creative use of communication technology and planning for those few times when the group can meet face-to-face due to limited resources. The advisory committee has a listserv but uses it sparingly, and there are two committees on the topics of evaluation and research that hold periodic calls. Over time, membership changes, and new members bring new ideas. The advisory committee has grown as large as 35 members and as small as 28 participants. If someone moves out of a position, that person has the option to remain on the advisory committee, as he or she often wants. Continuity makes a difference in the work of the advisory committee; some members of the advisory committee have witnessed research projects that began 10 years ago and are now bearing fruit with the full dataset and final analyses.

As noted previously, funding for the advisory committee comes from grants that provide resources to drive and fly in members twice a year and staff time to prepare for the meeting. One staff member serves as point-of-contact for members, another staff member leads each of the subcommittees, and four staff members attend each advisory committee meeting. Funding may come from other sources as well. For example, the Ohio Valley Center recently invited representatives from the Neurological Emergencies Treatment Trials Network, who engaged the advisory committee in community consultation, as part of Federal requirements for research in which consent is not possible.

If this role continues, there will be support for convening the advisory committee as well. In 2014, the advisory committee may meet only once in person and a second time virtually.

“If you give up early, you won’t get far,” says John Corrigan. “And if people are changing and you don’t communicate frequently, then you won’t get . . . [strong and lasting] . . . engagement.”

EDUCATION RESOURCE NETWORK: STAKEHOLDER DISSEMINATION

Phil Klebine, (<http://www.msktc.org/researchcenter/detail/UABTBI>) Assistant Director of Research

University of Alabama at Birmingham Spinal Cord Injury Model System

The Initial Research Question: Setting the Goal

(Stakeholder Topic Consultation)

When patients are discharged from the University of Alabama at Birmingham Spinal Cord Injury and Traumatic Brain Injury Model Systems (UAB-SCIMS & UAB-TBIMS), they are encouraged to have annual follow-up visits with a physician to monitor health-related issues. In addition to managing general health issues and standard screenings to identify potential problem issues, patients also need management of condition-specific health issues.

Many patients do not have access to a physiatrist (rehabilitation specialist) for health management, so they are encouraged to rely on a community-based primary care provider (PCP). However, patients commonly have difficulty locating a PCP with the education and training necessary to effectively provide both generalized healthcare and condition-specific healthcare.

The UAB team created a plan to develop a website to bridge that information gap and enhance PCP knowledge in managing SCI patients.

Who Is Involved?

(Stakeholder as Review Team Member)

Various stakeholder groups are involved in this initiative including UAB outpatient clinicians as well as consumers (people with SCI) and their PCPs. UAB builds the platforms for information availability and dissemination via an education resource network.

What Are They Doing?

(Stakeholder Input; Stakeholder Reaction)

To address the health-related issues of patients, the UAB-SCIMS and UAB-TBIMS Centers are establishing two Primary Care Provider Educational Resource Network websites, first in spinal cord injury and later in traumatic brain injury, designed exclusively for PCPs. Each website will be a one-stop location for finding available clinical practice guidelines and recommendations for general management of condition-specific medical issues. The websites will also provide situational advice on when referral for specialized services is warranted.

The clinical team at UAB reviews, verifies, and provides content for the websites. The content will include professionally oriented educational information indexed by topic. The website will also promote

the use of UAB's toll-free line, the Medical Information Service via Telephone (MIST), a 24-hour hotline for physicians to consult with a UAB specialist in SCI.

PCPs who use the UAB-SCIMS and UAB-TBIMS websites will have added benefits, including access to UAB's Medical Ambassador Program. The Medical Ambassador Program gives referring physicians a complete picture of their patients' visits to the UAB Health System, providing secure, timely, and complete online access to patient records, with their patients' permission.

How Will the Effectiveness of the Intervention Be Measured?

(Stakeholder Reaction)

UAB will include evaluation forms on the websites to be filled out by the users of the site, particularly the PCPs to whom the site is directed. There will also be a form specifically for questions and feedback. Feedback provided by the PCPs will guide future changes in content and design of the websites.

What Are the Dissemination Plans?

(Stakeholder Involvement with Dissemination)

The UAB team has planned a two-way approach to create awareness and use of the website. The "bottom up" approach provides UAB patients, families, caregivers, and other consumers with a wallet-sized information card to pass along to their community-based PCP. The card will contain information about the website and its purpose. The "top down" approach includes advertising locally and in State medical magazines and newsletters. UAB will also collaborate with the MSKTC in a similar effort to reach the medical audience on a national level.

Challenges and Solutions

The ultimate goal of the projects is to provide PCPs with the tools to improve the health of their patients with spinal cord injury or traumatic brain injury. Although PCPs and patients can complete surveys to evaluate the quality of services, the biggest challenge for UAB will be to effectively evaluate the actual health benefits to patients. There are currently no general models to provide such an evaluation.

Another challenge is finding the necessary time for content development. Clinicians are contributing content and providing reviews of the website, and the UAB team meets regularly to review the information and ensure that it is accurate and useful.

Exhibit 2. UAB's Draft Web Site for PCPs Who Serve Individuals with SCI



UAB SCHOOL OF MEDICINE
Knowledge that will change your world

[About the...](#) [SOM Quicklinks](#) [UAB Quicklinks](#)

Department of Physical Medicine and Rehabilitation



PRIMARY CARE PROVIDER EDUCATION RESOURCE NETWORK FOR SPINAL CORD INJURY

SCI CONDITIONS

- Bladder Dysfunction
- Patient Handouts
- Autonomic Dysreflexia
- Patient Handouts
-
- ADA Compliance Guides

Primary Care Provider Resource

The University of Alabama at Birmingham Spinal Cord Injury Model System (UAB-SCIMS) is devoted to making it easier for community-based primary care physician (PCPs) to find useful, up-to-date information from reliable sources for managing the healthcare needs of individuals with spinal cord injury (SCI). Here, we provide links to research-based treatment guidelines when available as well as offer general health management suggestions.

Why this website is needed...

The **Spinal Cord Injury Rehabilitation Evidence (SCIRE)** published **Primary Care for People with Spinal Cord Injury** with key points of interests.

- A large majority of people with SCI have a family doctor and are satisfied with care received.
- People with SCI tend to be high users of primary care.
- Lack of SCI-specific knowledge is a significant problem for people with SCI in primary care. There is evidence for inadequate knowledge of important secondary conditions and lack of adherence to clinical guidelines in treating SCI patients.
- Physical barriers are also encountered in some primary care practices.
- The majority of the issues raised by SCI patients in primary care are disability-related –specifically, they are secondary complications of the spinal cord injury.
- There is a high level of consistency in the literature on the most common issues raised by people with SCI in primary care.
- The most commonly raised issues are bowel, bladder and pain. Also of

800-UAB-MIST - 24-hour hotline for physicians to consult with a UAB specialist

[Ask Question](#)

[Contact](#)

This website is maintained by the University of Alabama at Birmingham Spinal Cord Injury Model System (UAB-SCIMS) and supported by grant #H133N110008 from the National Institute on Disability and Rehabilitation Research (NIDRR). Expressed opinions within this website are not necessarily those of the granting agency.



APPENDIX A. ALPHABETICAL LIST OF BIOS

Jennifer Bogner, Ph.D., Co-Principal Investigator, Ohio Regional TBI MS; Research Director, Ohio Valley Center for Brain Injury Prevention and Rehabilitation

Dr. Jennifer Bogner is the co-project director of the Ohio Regional Traumatic Brain Injury (TBI) Model System and the Research Director of the Ohio Valley Center for Brain Injury Prevention and Rehabilitation. She is also the vice chairperson of research and academic affairs for the Department of Physical Medicine and Rehabilitation at Ohio State University. She has worked in the field of TBI rehabilitation for more than 20 years, is a board certified rehabilitation psychologist, and associate professor in the Department of Physical Medicine and Rehabilitation at Ohio State University.

Michael L. Boninger, M.D., Director, University of Pittsburgh Model Center on Spinal Cord Injury

Dr. Boninger is professor and chairperson of the Department of Physical Medicine and Rehabilitation at the University of Pittsburgh and director of the University of Pittsburgh Medical Center Rehabilitation Institute. He is a professor in the Departments of Bioengineering and Rehabilitation Science and Technology and a physician researcher at the Department of Veterans Affairs. Dr. Boninger is the medical director of the Human Engineering Research Laboratories. Dr. Boninger received a mechanical engineering degree and doctorate of medicine from The Ohio State University. Dr. Boninger has authored or co-authored more than 180 publications and has been an invited speaker on assistive technology, wheelchair biomechanics, SCI rehabilitation, and secondary prevention of disabilities.

John Corrigan, Ph.D., Principal Investigator, Ohio Regional TBI MS; Director, Ohio Valley Center for Brain Injury Prevention and Rehabilitation

Dr. Corrigan is a professor in the Department of Physical Medicine and Rehabilitation at The Ohio State University, and director of the Ohio Valley Center for Brain Injury Prevention and Rehabilitation. He is principal investigator for the Ohio Regional Traumatic Brain Injury Model System. Dr. Corrigan chairs the executive committee of the TBI MS project directors. He is editor-in-chief of the *Journal of Head Trauma Rehabilitation*. Dr. Corrigan has received local and national awards for his service and research in the field, including the Brain Injury Association of America's William Fields Caveness Award and the 2007 Robert L. Moody Prize.

Tessa Hart, Ph.D., Principal Investigator

Moss Rehabilitation Research Institute Traumatic Brain Injury Model System

Dr. Hart is an institute scientist at Moss Rehabilitation Research Institute, where she directs the Traumatic Brain Injury Clinical Research Laboratory. A clinical neuropsychologist by training, she specializes in TBI treatment and outcome research in the areas of executive function, emotional regulation, and long-term psychosocial outcomes. She has also published on clinical trials and rehabilitation research methodology, with a focus on defining, measuring, and standardizing treatment. Dr. Hart is a Fellow of the American Congress of Rehabilitation Medicine and President-Elect of Division 22 of the American Psychological Association. She serves on multiple editorial boards and expert panels, including the Common Data Elements initiative.

**Radha Holavanahalli, Ph.D., Research Director
North Texas Burn Rehabilitation Model System**

Dr. Holavanahalli, associate professor, Department of Physical Medicine and Rehabilitation, is a medical sociologist. Dr. Holavanahalli has more than 20 years of experience in data management and analysis and 15 years of experience in burn rehabilitation research. She is the Vice Chair of the Aftercare and Reintegration Committee (a joint committee of the American Burn Association and the Phoenix Society for Burn Survivors) and the team leader for the group developing an online social skills training program to assist burn survivors with community re-entry. She serves as a member of the Model System Data Quality Committee and the MSKTC Advisory Committee. She is a certified instructor for Survivors Offering Assistance in Recovery, a peer-support training program developed by the Phoenix Society for Burn Survivors.

**Bethlyn Houlihan, M.S.W., M.P.H.
New England Regional Spinal Cord Injury Center Network**

Ms. Houlihan is the associate director of the New England Regional Spinal Cord Injury Center Network and has been managing the day-to-day research activities for more than 13 years. Ms. Houlihan received her master's degrees in Social Work and Public Health from Boston University. Her areas of expertise include project management, grant writing, outreach and dissemination, and applied sociomedical research for people with disabilities, particularly developing and testing interventions to improve care and outreach to people with spinal cord injury. Since 2004, Ms. Houlihan has served as a board member for the Greater Boston Chapter of the National Spinal Cord Injury Association. She is also co-chair for the Health & Disability Partnership through the Massachusetts Department of Public Health.

**Annmarie Kelleher, M.S., Lead Clinical Coordinator
Human Engineering Research Laboratories, University of Pittsburgh Model Center on Spinal
Cord Injury**

Ms. Kelleher received her bachelor's and master's of science degrees in Occupational Therapy from the University of Pittsburgh. She is currently working as the lead clinical coordinator at the Human Engineering Research Laboratories; a wheelchair seating clinician at the University of Pittsburgh Medical Center, Center for Assistive Technology; and a clinical instructor in the Department of Rehabilitation Science and Technology at the University of Pittsburgh. Knowledgeable in the proper administration of clinical studies involving human subjects, she is experienced in coordinating complex research projects. She is responsible for assisting in the development of clinical protocols and monitoring and participating in study implementation, subject recruitment, and data management.

**Phil Klebine, Assistant Director of Research
University of Alabama at Birmingham Spinal Cord Injury Model System**

Mr. Klebine is the assistant director of Research Services in the Department of Physical Medicine and Rehabilitation at the University of Alabama at Birmingham (UAB). He also serves on the Governor's Office on Disability State Advisory Council and is a board member for Disability Rights and Resources, a nonprofit organization that provides people with disabilities with services such as advocacy, peer support, independent living skills training, home modifications, nursing home transition, computer

training, work incentives, and referrals to community resources. UAB houses both a Spinal Cord Injury Model System and a Traumatic Brain Injury Model System.