



MSKTC
SCI • TBI • BURN

Model Systems
Knowledge Translation
Center

Engaging With Audiences: A Learning Collaborative

1–2:30 p.m., Tuesday, May 28, 2013



Welcome

- Welcome to the Webinar
- MSKTC Introductions

Agenda

- Welcome
- Types of Audiences
- Why Engage With Audiences?
- How To Engage With Audiences: Examples From the Model Systems
- Measuring the Quality of Engagement
- Discussion and Reflection

Types of Audiences

Types of Audiences

- What are the audience groups?
 - Patients, family, and caregivers
 - Clinicians and practitioners
 - Policymakers
 - Researchers—Outside the Model Systems

MSKTC Survey Results: Which Audiences Are Model Systems Engaging With?

How would you describe your current outreach efforts with each of the following audiences?

	High Activity (≥5 Times/Year)	Moderate Activity (2–4 Times/Year)	Low Activity (≤1 Time/Year)	Rating Average	Response Count
Non-MS* researchers	40.0% (18)	42.2% (19)	17.8% (8)	2.22	45
Clinicians & practitioners	54.3% (25)	41.3% (19)	4.3% (2)	2.5	46
Individuals with an injury & caregivers	60.0% (27)	33.3% (15)	6.7% (3)	2.53	45
Policymakers	13.3% (6)	33.3% (15)	53.3% (24)	1.6	45

Total Responses (N)=46

* Model System

Why Engage With Audiences?

Why Do Researchers Engage With Audiences?

- Identify the research needed and prioritize it
- Recruit people for research studies
- Create outcome measures and questionnaires that are useful to the end user
- Develop products that are useful to end users
- Increase the dissemination and use of the research
- Identify the barriers to implementing the research findings in practice

Why Do Audiences Engage With Researchers?

Stakeholders' motivations for participation include:

- Want answers to their questions and research to inform their interests
- Advancing scientific knowledge to contribute to the greater good
- Receiving financial compensation or incentives (e.g., training, materials)

(Mallery et al., 2012)

How To Engage With Audiences: Examples From the Model Systems

How To Engage With Audiences: Examples From the Model Systems

- **Radha Holavanahalli**—North Texas BMS
- **Tessa Hart**—Moss Rehab TBIMS
- **Bethlyn Houlihan**—Boston Medical Center SCIMS
- **Jenny Bogner and John Corrigan**—Ohio State University TBIMS
- **Annmarie Kelleher and Mike Boninger**—University of Pittsburgh SCIMS
- **Phil Klebine**—University of Alabama at Birmingham SCIMS

Building Trust With Patients: Working With Burn Survivors

Radha Holavanahalli, Ph.D.

Associate Professor, Department of Physical
Medicine and Rehabilitation, and Research
Director, North Texas

Burn Rehabilitation Model System (NTBRMS)

Building Trust With Patients: Working With Burn Survivors (continued)

Setting the Goal

- Build relationships and trust with burn injury patients through local groups, Phoenix Society for Burn Survivors, info sharing
- Determine relevance of research topics to burn survivors, who identified Social Skills as a topic of major focus

Who Is Involved?

- Burn survivors, Phoenix Society, and James Partridge of Changing Faces (in the United Kingdom)

Building Trust With Patients: Working With Burn Survivors (continued)

What Are Stakeholders Doing?

- **Provide input to study topics**—Is it relevant? Useful? Applicable to their lives?
- **Offer new ideas for topics**, e.g., social skills, community re-entry, heat sensitivity
- **Train peer support volunteers** for Survivors Offering Assistance in Recovery (SOAR)
- **“In their own words...”** video of burn survivors narrating their challenges in everyday life

Building Trust With Patients: Working With Burn Survivors (continued)

How To Measure the Effectiveness of the Intervention

- **Phoenix Society online social skills training**—Results pending; goal to test knowledge, practice, and health outcomes
- **Changing Faces 3–2–1–Go**—Results pending; ongoing intervention study, random assignment to training or control (no training) group
 - **Both groups**—Tested for social interaction anxiety
- **Quarterly Newsletter**—Burn survivors contribute; NTBRMS surveys readers regularly for usefulness

Building Trust With Patients: Working With Burn Survivors (continued)

What Are Dissemination Plans?

- “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.”
- Findings in newsletters used by patients and families
- Advisory committee members—Provide feedback on factsheets and input on effective dissemination plans
- Annual Phoenix Society conference for data collection and promotion of information to readership
- Burn survivors participate in education panel for nurses

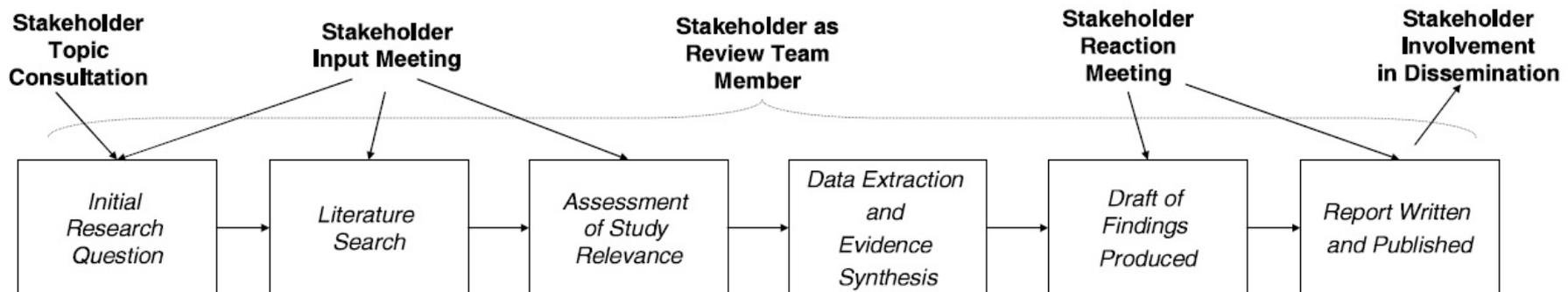
Building Trust With Patients: Working With Burn Survivors (continued)

Challenges and Solutions

- **Getting useful information to consumers:** “Burn survivors don’t always want to wait for research to be conducted on the information they need now.”
- **Connecting with hard-to-reach consumers:** Some live in isolation, not exposed to available resources, how to determine what issues impact them
- **Focus groups on long-term outcomes of burn injuries, aging with burn, etc.:** Need to consider these activities

Stakeholder Engagement Process

Stakeholder engagement opportunities



(Source: Keown, Van, & Irvin, 2008)

Engaging Patients, Families, and Clinicians in TBI Research

Tessa Hart, Ph.D.

Institute Scientist at Moss Rehabilitation Research Institute (MRRI), and Principal Investigator for the Traumatic Brain Injury Clinical Research Laboratory

Engaging Patients, Families, and Clinicians in TBI Research (continued)

Setting the Initial Research Question

- Conduct focus groups with stakeholders to learn:
 - Which topics are important to consumers?
 - What is important about that topic?
 - Is the topic feasible? What are the barriers to success?

Who Is Involved?

- Existing groups of patients; families or caregivers
- Clinicians at Moss Rehab; clinicians at conferences

Engaging Patients, Families, and Clinicians in TBI Research (continued)

What Are Stakeholders Doing?

- **Text messaging project for people with TBI**
 - **Questions:** Are they using it? In what way? What barriers exist?
 - **What we learned:**
 - How many people actually use texting; older people less so
 - How many would like to but cannot afford a phone
 - **As a result:**
 - Project designed a training program on how to text
 - Provide a pay-as-you-go phone if needed

Engaging Patients, Families, and Clinicians in TBI Research (continued)

What Are Stakeholders Doing?

- **Focus groups**—Family members confirmed the topic of study on pain measures; nurses gave input to scale items; family members offered ideas and refinements
- **Pilot studies**—With clinicians to review Moss Attention Rating Scale (MARS) to create and later weed out items; included clinicians outside Moss
- **Interviews**—Patient reviewed manual for TBI depression and anxiety; input used to revise manual
- **Pilot self-report questionnaire**—Revised per patient feedback

Engaging Patients, Families, and Clinicians in TBI Research (continued)

What Are Dissemination Plans?

■ **Annual 1-day Conference**

- Education and networking conference for people with TBI and family members
- A full year of planning to include consumers; consumers identify topics
- Workshops planned and conducted by clinicians and consumers teaching side by side

■ **Seminars in Rural Areas**

- Facilitate seminars for consumers in rural areas; developed toolkit for consumer groups to plan and run ongoing seminars

Engaging Patients, Families, and Clinicians in TBI Research (continued)

Challenges and Solutions

■ **Clinicians**

- Time constraints
- Not systematic in use of research findings in clinical care
- But...motivated to apply them in research and the development of tools

■ **Patients and Caregivers**

- Interested in sharing ideas and opinions

My Care, My Call: **SCI Stakeholder Engagement**

Bethlyn Houlihan, MSW, MPH

Associate Director, New England Regional Spinal
Cord Injury Center Network (NERSCICN)

My Care, My Call (continued)

Setting the Initial Research Question

- My Care, My Call (MCMC)—A project to engage stakeholders to develop and test an automated phone training for people with SCI to self-advocate in the PCP office

Who Is Involved?

- Content expert panel includes stakeholders that vetted the project idea, people with spinal cord injury (SCI), physical therapists, social workers, the Rehab Commissioner, et al. Provide a small stipend.

My Care, My Call (continued)

What Are Stakeholders Doing?

- **Phase 1**—Conceptualize flow of intervention, major themes to be addressed, and other critical considerations
- **Phase 2 (current)**—Expert panel will review and provide feedback on telehealth script in a “live test” format; also, pilot the training with 8 consumers through semistructured interviews after each call
- **Phase 3**—RCT w/ 60 consumers (30 intervention group, 30 usual care) for 9 months

My Care, My Call (continued)

How To Measure the Effectiveness of the Intervention

- Validated outcome measurement @ baseline and 9 mos.
 - *Hypothesis #1:* The MCMC telehealth module will increase users' self-advocacy in health care interactions as reflected in increases in three domains of self-advocacy: assertiveness, illness education, and potential for mindful nonadherence, compared with those receiving usual care.
 - *Hypothesis #2:* The MCMC intervention will increase users' self-efficacy for health care navigation, preference for involvement in, and satisfaction with their primary care physician (PCP) compared with those receiving usual care.

My Care, My Call (continued)

How To Measure the Effectiveness of the Intervention

■ Process data

- Use log contacts of patients to describe the number and pattern of calls, number of calls completed, and average ratings
- Examine user characteristics as predictors of system use
- Conduct a dose-response analysis
- Examine patient satisfaction data from exit interviews

My Care, My Call (continued)

What Are Dissemination Plans?

- The Expert Panel will:
 - Participate in presentations to community groups, conferences, consumer article publications
 - Vet consumer-focused materials (factsheets, reviews)
 - Disseminate findings to their networks
 - Promote the intervention if efficacious
 - Offer MCMC package nationally to membership of the United Spinal/National Spinal Cord Injury Association

My Care, My Call (continued)

Challenges and Solutions

- **Challenge**—Limited time and availability of panel members
- **Solution**—Conceptualize beforehand the scope and content of the tasks in a meaningful way for members, “chunk” out the work into reasonable units, set limits during calls to keep calls focused and brief
- **Lessons learned**—Important to keep the goal of the task and stakeholder role focused yet meaningful and honor the amount of time estimated to complete the task

Participatory Advisory Council: TBI Stakeholder Engagement

John Corrigan, Ph.D., PI for the Ohio Regional Traumatic Brain Injury Model System (ORTBIMS) and Director of the Ohio Valley Center (OVC) for Brain Injury Prevention and Rehabilitation

Jennifer Bogner, Ph.D., Co-PI for ORTBIMS and Research Director for OVC

Participatory Advisory Council: TBI Stakeholder Engagement (continued)

Setting the Goal

- Establish a participatory advisory council (AC) for the OVC that serves Ohio, Indiana, Virginia, West Virginia and Michigan. Meet twice annually, calls, listserv

Who Is Involved?

- Primary and secondary consumers, advocates, State brain injury association reps, clinicians, and policymakers (State government agency staff)

Participatory Advisory Council: TBI Stakeholder Engagement (continued)

What Are Stakeholders Doing?

- **Participatory action** from concept development to proposal review; help with refinement from implementation to interpretation
- **Envisioning process** every 5 years; create vision and strategic plan to identify and prioritize the major issues facing the field; identify main focus areas; guide types of grants to search and apply for
- **AC meetings** include focus on OVC's work, subcommittee reports, input from AC to projects, and sharing "news from home"

Participatory Advisory Council: TBI Stakeholder Engagement (continued)

What Are Dissemination Plans?

- OVC disseminates findings from studies via State and national conferences
- AC members who sponsor conferences frequently invite us to speak (free for our participating States)
- Brain Injury Association of American (BIAA) recently invited us to do a Webinar on substance abuse for caregivers
- We provide synopses of two published works to BIAA for their Web site and/or *The Challenge*; the AC's Research subcommittee reviews for consumer friendliness

Participatory Advisory Council: TBI Stakeholder Engagement (continued)

What Is a Brain Injury Advisory Committee (BIAC)?

- Most States have a BIAC (supported by grants from the Health Resources and Services Administration)
- Core conditions for establishing a BIAC
 - a designated entity/individual in the State to lead planning and policy
 - composed of policymakers and other stakeholders
 - a completed needs assessment
 - a completed action plan
- Note: These policymakers are State agency staff, not elected officials

Participatory Advisory Council: TBI Stakeholder Engagement (continued)

Challenges and Solutions

- Get started. In the beginning, AC members wanted to “tell their story.” Let them do that.
- Communicate frequently. Number of in-person meetings depends on grant funding; conference calls or online meetings supplement in-person meetings
- Continuity vs. turnover. Continuity is important, but turnover brings new ideas; allow former members to remain. (They do.)
- Staff resources. Includes director, contact/coordinator, and subcommittee liaisons; four attend in-person meetings

Participatory Engagement in Wheelchair Design for SCI Users

Mike Boninger, M.D.

Professor and Chair, Department of Physical Medicine and Rehabilitation, University of Pittsburgh; Medical Director, Human Engineering Research Laboratories; and Director, University of Pittsburgh Model Center on Spinal Cord Injury (UPMC-SCI)

Annmarie Kelleher, M.S.

Lead Clinical Coordinator, Human Engineering Research Laboratories; Clinical Instructor, Department of Rehabilitation Science & Technology, University of Pittsburgh; and Wheelchair Seating Clinician, UPMC-Center for Assistive Technology

Participatory Engagement in Wheelchair Design for SCI Users (continued)

Setting the Goal

- Participatory design format to engage people with SCI in engineering tasks, designs, and development for wheelchairs

Who Is Involved?

- Wheelchair users recruited from events who would benefit from the technology
- Research team (researchers, data collector, rehab counselors, psychologist, grad students) includes individuals with SCI

Participatory Engagement in Wheelchair Design for SCI Users (continued)

What Are Stakeholders Doing?

- Provide input through all phases of design, development, and testing
- Early prototype—Feedback on how it could be used
- Focus groups—What they like/dislike about the product
- Reflection on feedback, redesign if needed
- In-lab testing and evaluation in a structured environment
- In-home testing and evaluation to ensure the product is functional and useful; then 1:1 interviews/questionnaires back in the lab

Participatory Engagement in Wheelchair Design for SCI Users (continued)

How To Measure the Effectiveness of the Intervention

- Stakeholder feedback throughout all phases of design and development improves the effectiveness of technology
- Measured by researchers, then incorporated into stages of development
- Can include standardized questionnaires, clinical and research assessment tools, and interviews
- Ultimate goal is increased participation, so include participation and quality-of-life metrics

Participatory Engagement in Wheelchair Design for SCI Users (continued)

What Are Dissemination Plans?

- Submit to peer-reviewed research journals and publications
- Distribute abstracts and articles to consumer-oriented publications
- Develop consumer-oriented clinical practice guidelines for Paralyzed Veterans of America and MSKTC
- Disseminate research results to 2,000+ newsletter recipients and registry participants
- Present to local disability organizations and support groups
- SCI peer support group discussions

Participatory Engagement in Wheelchair Design for SCI Users (continued)

Challenges and Solutions

- **Logistics**—Individuals with SCI may have transportation challenges or require caregiver assistance
- **Social media**—How to use this tool to communicate; are people with SCI using these communication tools?

Education Resource Network: Stakeholder Dissemination

Phil Klebine, M.A.

Assistant Director of Research Services,
Department of Physical Medicine and
Rehabilitation, University of Alabama at
Birmingham (UAB)

Spinal Cord Injury Model System (SCIMS) and
Traumatic Brain Injury Model System (TBIMS)

Education Resource Network: Stakeholder Dissemination (continued)

UAB SCI & TBI Model Systems

- 2 new websites (SCI & TBI) that offer primary care providers (PCPs)
 - a one-stop location for clinical practice guidelines and recommendations for conditional medical management
 - situational advice on warranted referrals to specialized services

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
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PRIMARY CARE PROVIDER EDUCATION RESOURCE NETWORK FOR SPINAL CORD INJURY

SCI CONDITIONS

Bladder Dysfunction

Patient Handouts

Autonomic Dysreflexia

Patient Handouts

—
ADA Compliance Guides

Bladder Dysfunction – PCP Information

In the context of spinal cord injury, bladder dysfunction occurs when there has been damage to the central nervous system, specifically the spinal cord. The insult prevents communication between the central nervous system micturition center, located in the rostral pons, and the peripheral nerves which control detrusor muscle activity, primarily the pudendal and pelvic splanchnic nerves.

As a result of this disruption in communication, voluntary control of urination is affected. Exact changes vary based on the level of spinal cord injury. Emptying is incomplete with either high pressure or low pressure residual volumes. Bladder dysfunction differences are based on the level neurologic disruption.

- **Upper Motor Neuron**
- **Lower Motor Neuron**

Conditions:

- **Urinary Tract Infection**
- **Calculi**
- **Renal damage secondary to Vesicoureteral reflux**

Notes:

Beginning in year 1 post-injury, patients should be evaluated annually by a Urologist with specific knowledge in urologic care of patients with spinal cord injury.

Resources

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

Ask Question

Contact

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Education Resource Network: Stakeholder Dissemination (continued)

UAB SCI & TBI Model Systems

- Bottom-up & top-down dissemination approach:
 - Bottom up – offer wallet-size cards to consumers (patients, caregivers, other)
 - Top down – locally, plan to advertise in state medical magazines and newsletters to generate website awareness and use. Also, collaborate with MSKTC in a similar effort to reach the medical audience on a national level



HEALTH CARE PROFESSIONAL

UAB PROVIDES MEDICAL PROFESSIONALS WITH GENERAL TREATMENT GUIDELINES AND RECOMMENDATIONS FOR PRIMARY CARE MANAGEMENT OF PATIENTS WITH SPINAL CORD INJURY.

UAB MEDICINE

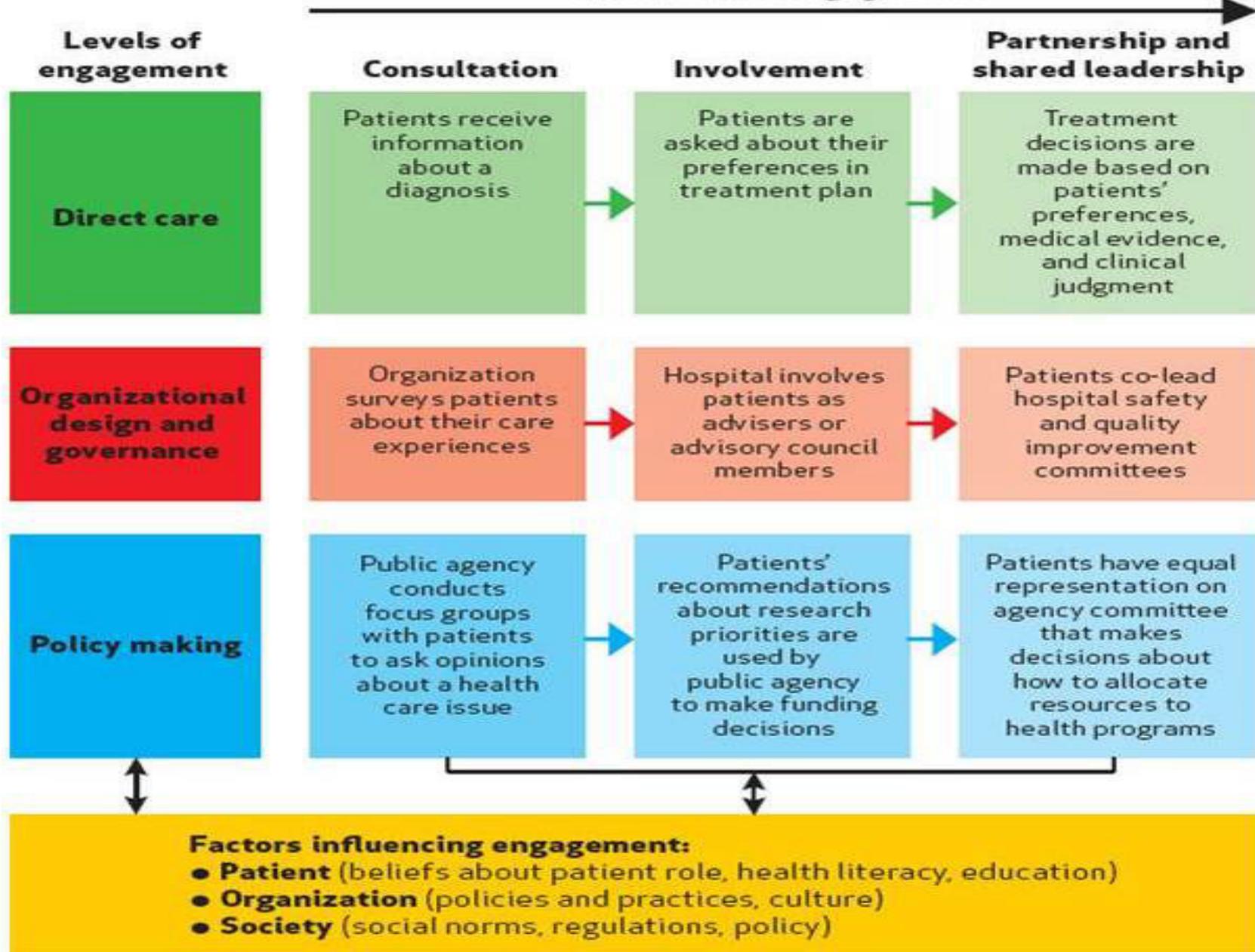
PHYSICAL MEDICINE AND REHABILITATION

A PRODUCT OF THE
UAB SPINAL CORD INJURY MODEL SYSTEM

WWW.UAB.EDU/SCIPC

Measuring the Quality of Engagement

Continuum of engagement



(Source: Carman, Dardess, Maurer, et al., 2013)

Measuring Process and Outcomes

- Process: Was the stakeholder able to fully engage in the appropriate role for the project/decision?
- Outcome: Is the end result a stakeholder-centered
 - Decision
 - Process
 - Policy
 - Service
 - Dissemination Plan
 - Educational material

Key Questions

- Are we reaching level of engagement that is most appropriate for this project/situation?
- Did engagement yield a stakeholder-centered outcome?
Does the outcome reflect stakeholder interests and ideas?
- Do the stakeholders feel satisfied with the engagement process?
- Do stakeholders feel their interests and ideas are reflected in the outcome?
- Do stakeholders feel a sense of ownership in the outcome?
- Are stakeholders fully activated?

Possible Survey Questions

(Likert Scale Agreement)

- I felt I had the information I needed to participate fully.
- I felt capable to participate in the discussion(s).
- I felt clear about the role I played in making decisions.
- I wish I had been allowed to play a larger role.
- I felt that I was integrated fully into meetings and discussions.
- I felt that (doctor, researcher, administrator) took my input, questions, and ideas seriously.
- I saw my input and ideas reflected in the final outcome.
- I was actively involved in the final decisions that were made.
- I felt like I was a full partner in these decisions.

Discussion & Reflection

Examples From Your Model System

- Discussion
 - What does your audience engagement look like?
 - What have been some successes from that engagement?
 - What have been some challenges? How have you addressed them?

Reflection Questions

- What resonates with you in the examples shared?
- What new idea did you learn that you would consider applying in your work?
- What would you have to adapt or change in your research system to accommodate engagement?
- What process or outcome measures of stakeholder engagement might you add to your processes?

Questions?

- Please contact us at MSKTC@air.org with more questions or ideas for future Webinars (KT topics)
- Complete the online evaluation form; a link will be sent to all registrants

Thank You!

- Dr. Radha Holavanahalli
- Dr. Tessa Hart
- Bethlyn Houlihan
- Dr. Jennifer Bogner and Dr. John Corrigan
- Annmarie Kelleher and Dr. Michael Boninger
- Phil Klebine

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