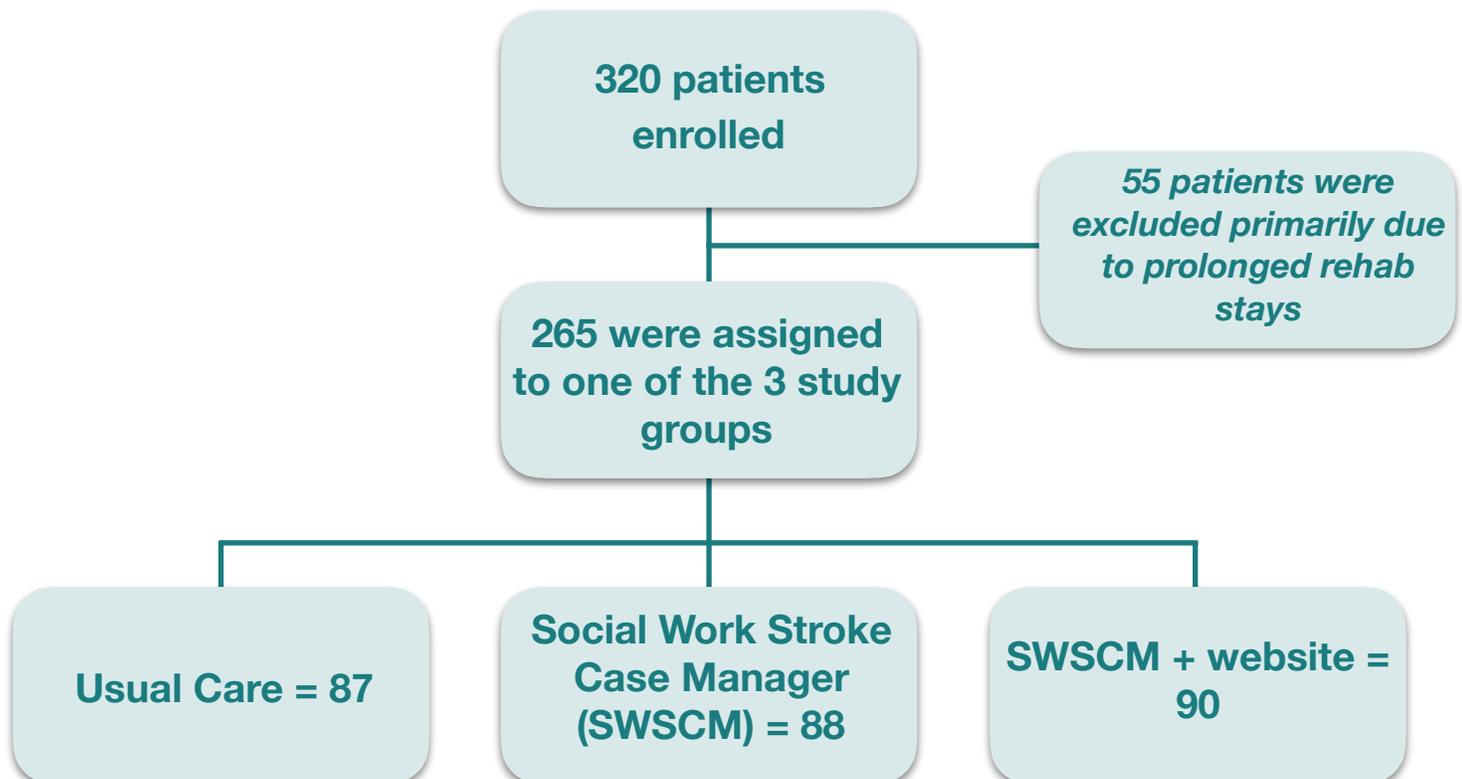


## SAVE THE DATE

The FINAL Advisory Board meeting is scheduled for **Wednesday February 7, 2018, 4:00-6:00pm** at the MSU Federal Credit Union Community Room (same location as last meeting). We look forward to seeing you all the then to celebrate the completion of the MISTT study!

**We are pleased to announce that we achieved our enrollment goals and have finished all data collection for the MISTT study!** This was accomplished due to the tremendous efforts of our incredible team including the hospital staff who recruited the patients and caregivers, the social work case managers who conducted the intervention, and our team of data collectors who conducted the telephone interviews at the 7- and 90 day time points.

Recruitment ended the end of July 2017 after enrolling **320 patients and 210 caregivers**. Although some of these patients ultimately could not participate due to a prolonged rehab stay, 265 were assigned to one of the three study groups; see figure. Our social workers finished their case management in October, and the final 90-day phone interviews were completed in early December. Of the 265 subjects randomized to receive one of the MISTT interventions we were able to collect data on 240 (91%) patients. Of the 169 caregivers who were randomized we were able to collect data on 148 (88%). These are very high rates of data completion which points to the diligence and hard work of the entire MISTT team.



## SOCIAL WORK CASE MANAGEMENT SUMMARY

In early October we said goodbye to our wonderful Social Work Case Managers. These four women, Kristen Boeskool and Deb Montgomery in the Lansing area, and Amy Nagaj and Diane Fuselier-Thompson in the Ann Arbor area provided excellent service to the patients and caregivers in Groups 2 and 3. Social work case managers completed comprehensive biopsychosocial assessments that, in conjunction with patient and caregiver wishes, informed the support given in each case. At times this support was straightforward, such as when they provided referrals to community resources. At other times, the support was more complex, such as when the patient or caregiver needed more emotional support, or were faced with a financial crisis after their stroke. On average each case received 26 contacts from our case managers, completed via phone call or home visit. The case managers found this work to be very valuable and were encouraged to see the positive impact that they had on their clients. Anecdotal feedback from patients and caregivers support the important role that the case managers played in managing the transition home after stroke.

### WHAT'S NEXT?

#### DATA ANALYSIS AND DISSEMINATION OF STUDY RESULTS

**Data Analysis:** We are currently analyzing our study outcomes to learn if either of the two interventions: the Social Work Case Management program and the Website improved patient and caregiver experiences. As a reminder the study chose to examine a global quality of life scale (PROMIS-10) and a measure of patient self-management and activation (PAM). We will share our results during the next Advisory Board meeting, scheduled on February 7, 2018.

**Fact sheets:** Thank you for all of your thoughtful feedback in helping us create and refine our dissemination materials. We have included the final versions of 3 factsheets that we are now beginning to share with stroke patients, family members, health professionals, and community organizations. The 3 factsheets are titled:

1. *Some Things to Know When you Return Home after a Stroke,*
2. *Communicating with Your Healthcare Team,* and
3. *Stroke and Stroke Recovery Can Strain Your Finances*

We are also working on two additional factsheets – one for caregivers and one for healthcare professionals. We will reach out to you again soon asking you to review our drafts and provide feedback about the content and format.

#### DISSEMINATION STRATEGY - HOW YOU HAVE HELPED?

At the last Advisory Board meeting (July 2017) you participated in a group exercise to help us further explore and prioritize: 1) Who should know about stroke transitions, 2) Where/how we can educate about stroke transitions, and 3) What information we should be providing about stroke transitions. We are using the results of this exercise to guide our dissemination strategy. The following is a condensed summary of what you came up with during the July discussion:

##### Q1. Who should know about stroke transitions?

- i. Three main groups of people were identified: 1) Informal caregivers including family and others who have personal relationships with a patient, 2) Formal caregivers including healthcare professionals involved with patient care, and 3) Community-level organizations providing services or social/recreational support to patients.
- ii. Of these groups, informing family, interdisciplinary care teams, and home healthcare agencies were given highest priority.

- iii. The advisory board members also suggested that friends, senior centers, and transportation services need to know about stroke transitions.

## **Q2. Where/How can we educate about stroke transitions?**

- i. Various healthcare locations and community-level facilities were identified as places to educate about stroke. Highest priority was given to community-level organizations including housing authorities and the AARP. Senior centers and waiting areas (doctor office, rehab facility, pharmacy, etc.) were also mentioned.
- ii. Board members suggested a variety of ways to disseminate stroke information ranging from speaking at support groups or healthcare staff meetings to generating media-related messages for dissemination. But the highest priority was given to providing information in the discharge paperwork used by hospitals and rehab facilities and in using community news alerts. Hospital portals and social media were also mentioned but given lower priority.

## **Q3. What information should we be providing about stroke transitions?**

- i. The group discussions identified four major education themes including: 1) Describing the range of stroke effects, 2) Coping skills for adjusting to a “new normal”, 3) How to assess patient and caregiver needs, and 4) How to assess and educate about community-wide factors such as insurance financial issues, insurance coverage, community resources, and accessing reliable information about stroke.
- ii. The highest priority was given to educating about coping skills and adjusting to a “new normal.” Comments that addressed this important area included helping normalize the recovery process by sharing things like you can never be 100% prepared; it is normal to be overwhelmed, anxious, and fatigued; both patients and caregivers need a support system and good listener; and that recovery is a process that requires evolution and new adjustments.
- iii. Evaluating community-level factors were given medium priority. Specifically, financial coverage for medications, available community resources and support systems – for example, stroke support groups, local food pantries, short and long-term financial support, and finding accurate health information were mentioned.

The MISTT research team has found the information provided through this exercise to be extremely helpful. It has been especially useful for prioritizing our dissemination activities in terms of specific content and targets – we simply can’t disseminate everything relevant to stroke to everyone who might need it. We thank you for helping us identify new, important dissemination strategies that we hadn’t considered before. We also hope you found the exercise valuable as an opportunity to learn from your fellow Advisory Board members!

## **SUMMARY OF ADVISORY BOARD SURVEY**

After the July 2017 Advisory Board meeting we asked board members to complete a short survey to help us understand their experiences as an Advisory Board member and to guide improvements for upcoming activities.

THANK YOU to all who completed the survey! We received responses from 2 stroke survivors, 1 caregiver, and 3 health professionals. A summary of the responses to the 5 survey questions include:

### **Q1. What does it mean to you to be an Advisory Board member?**

- i. Respondents reported that being an Advisory Board member meant learning

things about stroke, sharing them with others (both personally and professionally), and contributing knowledge from their unique perspective and experience.

- ii. Stroke survivors also emphasized the importance of sharing their personal stroke story, representing other survivors' perspectives, and learning about the range of healthcare support available for stroke.
- iii. Healthcare professionals saw the Advisory Board as an opportunity to collaborate and improve current clinical practice for the post-discharge period.

**Q2. What was the main reason you wanted to participate?**

- i. Learning more about stroke was reported as the common motivation for joining the Advisory Board.

**Q3. How much influence do you think you have had so far?**

- i. Most members felt that their influence on the overall project was modest.

**Q4. How satisfied are you with how the study has sought your input?**

- i. All members reported being satisfied or very satisfied with their participation.

**Q5. What suggestions do you have to improve the study?**

- i. Suggestions for improving MISTT processes focused largely on dissemination activities including learning about MISTT results and outcomes; hearing about the feedback from wider audiences, such as those at conferences and other presentations; getting updates about new MISTT publications; obtaining access to the new MISTT website ([mistt.msu.edu](http://mistt.msu.edu)); and improving collaboration between academia and clinical practice.
- ii. Members emphasized that dissemination materials should have clear, simple language and use large font. They also suggested that technology use may vary between different groups with stroke (i.e., younger stroke survivors may be more willing to use technology); to advocate for insurance to pay for social work services; and requested regular Advisory Board updates.

Again, thank you to those members who completed the survey. We believe that these responses help illustrate the benefits of having an Advisory Board as part of our MISTT study. We will use your suggestions to revise our upcoming activities so that we can better emphasize the things that are important to our Advisory Board members. While the Advisory Board members who responded thought that they had only modest influence on the study, we want you to know that we greatly appreciate your contributions and know that this study is better because of YOUR INVOLVEMENT!

**Happy Holidays, and we look forward to seeing you on February 7th 2018 at 4:00pm!**