

How PFAC is making a difference in the STAMP Study!

Update from the 9/30/17 meeting

Topic

PFAC Feedback

Impact

Opportunities for increasing interest and enrollment & decreasing barriers to participation

Feedback on recruitment mailing content and presentation

The PFAC members reviewed the recruitment mailing sent to people identified through Electronic Health Records as potentially eligible.

Current mailing includes:

- Healthcare system letter
- Researcher letter (signed by Dr. Z)
- Brochure
- Opt-out card

The PFAC provided constructive feedback on the mailing and made the following suggestions:

- Reorganize the pieces in the mailing so the letters and opt-out card are stuffed inside the brochure – so the first thing people see when opening the envelope is the brochure
- Consider having only one letter instead of two
- Shorten researcher letter
- Suggested phrases such as “strong pain medications” and “opioid medication” should not be used in recruitment materials, as it is likely to send up red flags

- The research team immediately changed how envelopes were stuffed
- The Researcher letter was revised based on PFAC feedback
- Do to regulatory and administrative requirements, the healthcare system letter could not be changed or removed

Feedback on “Opt-out card”:

The research team explained we are receiving back more “op-out” cards than we expect, and asked if the cards could be confusing and people are mailing them back wanting to be contacted.

The PFAC provided the following comments & suggestions:

- They did think the card might be confusing, as the term “opt-out” is not common language.
- They recommended we change it to “Response Cards” and have check-box options for both “Yes, please contact me with more information” and “No, I am not interested”.
- They also recommend changing the color of the card away from bright orange to white or light blue, so the card will not draw too much attention.

- The card will be changed based on PFAC feedback
- We are getting a substantial number of cards returned with “Yes, please contact me”

Example feedback provided to stakeholders after each meeting

Feedback on phone message:		
<p>The research team explained that we have very few people calling us back in response to research coordinators leaving voice mail messages.</p> <p>PFAC members were given a copy of the phone message script for their feedback</p>	<ul style="list-style-type: none">• PFAC members provided constructive feedback on the script, including making the language less formal and warmer• Suggested research coordinators could receive additional training on script delivery and periodic quality checks to ensure consistent message delivery	<ul style="list-style-type: none">• The script will be revised based on PFAC feedback.

Example agenda



Department of Family Medicine
and Community Health
UNIVERSITY OF WISCONSIN
SCHOOL OF MEDICINE AND PUBLIC HEALTH

STAMP: Strategies to Assist with Management of Pain

Patient Family Advisory Committee (PFAC) Meeting

March 3, 2018

10:00 a.m. – 11:30 a.m.

Wingra Family Medical Center, Bay Creek Conference room
1102 S. Park St., Madison, WI

Agenda

9:45 - 9:55 am: Arrival and light breakfast

10:00 am: Welcome and opening question

Alice Yuroff (STAMP Stakeholder Engagement Coordinator) and PFAC

Go around the table, please share your name, and answer this question: “What is one creative thing or hobby that you do outside of these PFAC meetings?”

10:15 am: How the PFAC is making a difference &

Update from 10-16-18 Stakeholder Advisory Committee meeting

Alice

10:25 am: Project and recruitment update

Aleksandra Zgierska (STAMP Lead Researcher) and Cindy Burzinski (STAMP Study Manager)

10:30 am: Feedback on STAMP Study website (small group activity)

PFAC

11:15 am: Feedback on STAMP Study ad graphics

PFAC

11:25 am: Evaluation

PFAC

11:30 am: End meeting

Room available until 12:00 pm for continuing conversations

Example agenda



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Strategies to Assist with Management of Pain (STAMP) Study

4th Stakeholder Advisory Committee (SAC) Meeting

Tuesday, October 9, 2018; 8:30-11:30 am CST
Department of Family Medicine, 2nd floor Wisconsin Room
1100 Delaplaine Ct. Madison, WI 53715

Agenda

- 8:30 am Arrival, networking activity and breakfast
- 9:00 am Welcome and introductions
Alice Yuroff (Study Stakeholder Engagement Coordinator)
- 9:15 am Project update
Overall progress: Aleksandra Zgierska (STAMP Lead Researcher),
Madison updates: Aleksandra Zgierska (Researcher)
Boston updates: Robert Edwards (Researcher)
Salt Lake City updates: Yoshio Nakamura (Researcher)
- 9:30 am Updates from:
3/19/2018 SAC meeting
10/8/18 Patient and Family Advisory Committee (PFAC) meeting
Alice Yuroff and PFAC members
- 9:40 am Group discussion: How to decide which study participants to select for in-depth exit interviews
Cindy Burzinski (STAMP Study Manager) and SAC members
- 10:30 am Group discussion: strategies to increase physician referral of patients to the study
Rachel Atchley (Salt Lake City STAMP Study Manager) and SAC
- 10:55 am Group Discussion: strategies for community outreach recruitment
Christina McDonnell (Boston STAMP Study Manager) and SAC
- 11:15 am Upcoming SAC activities:
Scheduling of our next meeting (bring your calendars)
Information on the IRB-required training
- 11:25 am Meeting evaluation
- 11:30 am Adjourn
- 11:30 -11:45 am Room available for continuing conversation

Evaluation: October 9, 2018: Stakeholder Advisory Committee Meeting

Please answer each question below by making a check mark in the appropriate box.

How did you like the following activities?

	Liked very much	Liked	Did not like	Did not like at all
Icebreaker game during breakfast				
Introduction & opening question				
Project & recruitment update				
Discussion: How to decide which study participants to select for in-depth exit interviews				
Discussion: strategies to increase physician referral of patients to the study				

What did you think of the meeting facilitators?

	Always	Usually	A few times	Never
Did they present material clearly?				
Did they give you enough time to make comments and ask questions?				
Did they do a good job answering questions?				
Did they do a good job making sure everyone's ideas and comments were heard?				
Did they effectively include people participating via phone and/or webinar?				

Comments:

What changes would you make to improve our SAC?

Thank you!



The Wisconsin Network for Research Support

Innovative Services for Patient and Community Engagement

Who we are

Wisconsin Network for Research Support (WINRS) is an innovative and nationally-recognized patient and community engagement resource, based at the UW-Madison School of Nursing. Since 2010, WINRS has offered a suite of consultation services to address a persistent problem for researchers – how to effectively connect and communicate with study participants, especially people from under-represented communities. WINRS services are relevant for any researchers who want to engage diverse research participants and study stakeholders.

Staff: Gay Thomas, MA; Betty Kaiser, PhD, RN; Katrina Phelps, PhD

WINRS services

For researchers without funding: WINRS provides initial, no-cost consultations to:

- Share strategies for recruiting, working with, and retaining diverse populations of study participants and stakeholders
- Review and edit recruitment and stakeholder engagement plans in grant proposals
- Offer advice on budgeting for successful recruitment and stakeholder engagement
- Determine optimal fit between researcher needs and WINRS services
- Suggest additional resources or strategies that might benefit the researcher's program of research

For researchers with funding: WINRS' services are relevant across the full life cycle of research projects, available both to researchers at the UW-Madison and to research teams at other sites.

- Advise on recruiting study participants and stakeholders/patient advisors
- Coordinate meetings with Community Advisors on Research Design and Strategies (CARDS)[®] -- unique focus groups of diverse community members who give feedback on recruitment materials, consent forms, survey/focus group questions, websites, smart phone apps, and more
- Help researchers tailor WINRS toolkit materials for their own target populations
- Provide consultation to develop project-specific patient advisory boards, plan effective stakeholder meetings, and sustain engagement
- Design and conduct focus groups
- Provide "Plain Language editing" of any patient or public-facing materials
- Help develop dissemination strategies and presentations for lay audiences

WINRS toolkits:

- Hard-to-Reach Patient Stakeholders: An Engagement Guide (HARPS) <https://www.hipxchange.org/HARPS>
- Patient Advisor Toolkit I: Orientation for Patient Advisory Committees <https://www.hipxchange.org/PAT-I>

Other:

WINRS staff offer workshops/presentations on a range of topics including engaging patients in research, working with community partners and community advisory groups, and using Plain Language. They also conduct "train-the-trainer" sessions on implementing their engagement toolkits.

More information: Please explore the [WINRS website](#) or email us winrs@son.wisc.edu



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Community-Academic Partnerships
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