



# NINDS INSPIRE Workshop

Improving Neurology Subject (and Provider) Participation In the Research Enterprise

June 20 – 21, 2013

NIH Neuroscience Center in Bethesda, MD

**Group 2 Communication: Consent, Outreach, Messaging, Motivating and Social Marketing**  
**Session Co-Chairs: Peggy Clark, RN, MSN, PNP, Chris Speed, & Barbara Tilley, PhD**

## Outline:

1. Developing a strategic communications plan for neurological studies
2. Using a communications model for success
3. Communicating effectively before, during and after the recruitment process
4. Utilizing resources and partnerships

## Session I: Developing a strategic communications plan for neurological studies

*(following Panel I)*

- 1) How do you develop a strategic communication plan in advance of recruitment?
- 2) What makes communicating with neuro populations different and more difficult (e.g. rarity of disease, acute vs. chronic studies, different audiences that may need to be identified)?
- 3) What considerations/principles do you need to consider to develop a document/checklist/framework or similar tool to that can serve as a starting point?
- 4) Are there tools available that can facilitate more effective communications planning? Would logic models be useful?
- 5) Can we develop a flow chart or decision tree that would allow study teams to answer questions about the specific needs of a given study (e.g. study type, patient population, target audiences, etc.) that a good communication plan should include?



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## **Session II: Using a communications model for success**

*(following Plenary I)*

**WHO:** Primary and secondary audience identification

- 1) Who is the primary audience that you are talking to? *(Potential participants? Those who are in a position to influence potential participants? Champions in the community?)*
- 2) What is the level of engagement of the target population and advocacy groups in your community when it comes to clinical research?

**WHAT:** Determining messages

- 1) What message do you need to convey? What do they hear when you say it?
- 2) What is going to make them pay attention to your message? *(Emotion? Personal relevance? Facts?)*
- 3) How do you develop culturally sensitive, relevant and meaningful messages about the benefits of clinical research participation for various communities? *(What role do demographics play? Other factors?)*
- 4) What is the outcome you're looking for?

**WHERE/HOW:** Outreach Planning

- 1) What are the best means to reach your audience? *(TV/radio/print? Online/social media?)*
- 2) Who do they trust? *(Community gatekeepers? Medical practitioners?)*
- 3) What media outlets make the most sense for your budget?

**WHY:**

- 1) Why should they be interested *(Altruism vs. Realism? What's in it for them?)*



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## **Session III: Communicating effectively before, during and after the recruitment process** (following Panel II)

- 1) What are the best ways to reach your target audience(s) before, during and after the recruitment process?
- 2) What models have worked or not worked? (*case studies, exercises, messaging issues*)
- 3) Are you creating awareness or do you want recipients to take action? At what stage?
- 4) Communication and consent: are we asking the right questions?
- 5) What are the characteristics/clues that a subject may not be a good fit (*e.g. that they may not be committed to staying in the study, that they may not be adherent to the treatment regimen*)?
- 6) What is the role of performance tracking? (*How will you know when tactics are working? What do you do if an expensive tactic is not working?*)

## **Session IV: Utilizing resources and partnerships** (following Panel III)

- 1) Is the target audience (*patient, provider, lay community*) aware of the study or need for the study and can you leverage that awareness?
- 2) How can engaging advocacy groups benefit the neurological clinical research enterprise?
- 3) What do the advocacy groups need from research teams? What do research teams need from the advocacy groups?
- 4) What is the breadth of minority representation in advocacy groups?
- 5) How do you access and engage the communications experts at your local institution and at NINDS?
- 6) How do we change the culture to something similar to Pediatric Oncology Research (every patient in a trial)?
- 7) How can you better engage and inform the public about the social good that is clinical research? What is your role in improving awareness?