AGENDA
SMART (Social Media & Research Toolkit) WORKSHOP
PCORI Engagement Award (EAIN-3989)

1) Welcome Remarks & Introduction 10:00 a.m. – 10:30 a.m.
   o Who's who around the table

2) Why understanding the impact of social media is important for healthcare research: Research, PROs & social media platforms (Shilpa, Ben, Joe)
   Format: Roundtable discussion 10:30 a.m. – 11:30 p.m.
   - Social media as a form of data collection: structured versus unstructured data
     o Concept elicitation as a best practice strategy to use unstructured data.
     o Tracking, observing and reporting: Pathway from observation to research topic prioritization
     o Respecting patient confidentiality

3) Patient-Clinician Interface in Research: Getting patients involved in the phases of research: Phase 1 – Research Topic Prioritization
   Format: Roundtable discussion 11:30 a.m. -12:15 a.m.
   - Best practices around research topic prioritization: What are some areas of topics that clinicians are still trying to understand?
     o Can structured questions by clinicians/researchers to patients help identify and prioritize research topics?
   - Activity using SpA as an example

LUNCH BREAK 12:15 P.M. – 1:15 P.M.

4) Engaging the patient community: Phase 2 or ‘during’ the research study
   Format: Roundtable discussion 1:15 p.m. -2:30 p.m.
   - Building a best practices guide on how to do a literature review within existing online resources and peer reviewed publication on SpA studies
   - Recruitment efforts in reaching Psoriatic Arthritis and Ankylosing Spondylitis patients online: Identifying target populations through patient leaders online & building best practices for recruitment

5) Using research to engage in advocacy online: Phase 3 or ‘after’ the research has been conducted
   Format: Roundtable discussion 2:30 p.m. – 3:30 p.m.
   - Dissemination of research findings within the SpA community: Best practices
   - How to be heard: Building templates for emails and tweets to local government representatives for the SpA community of patient advocates
   - Best practices for patient to patient outreach - Community outreach within the SpA community

COFFEE BREAK 3:30 p.m.- 4:00 p.m.

6) Next steps & Wrap up 4:00 p.m. -5:00 p.m.
   - Pulling together best practices & developing the toolkit

THANK YOU FOR ATTENDING
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