SMART
Eugene Washington PCORI Engagement Award (3989-GHLF)

The Social Media and Research Toolkit (SMART)
MULTI-STAKEHOLDER ROUNDTABLE WORKSHOP—NEW YORK

Friday, August 18, 2017
10:00 a.m. - 5:00 p.m. Eastern

GLOBAL HEALTHY LIVING FOUNDATION (GHLF)

- Shilpa Venkatachalam, GHLF, Project Lead and Facilitator
- Ben Nowell, GHLF, Project Advisor and Co-Facilitator
- Joe Coe, GHLF, Social Media Expert and Co-Facilitator
- Rachael Langa, GHLF, Research Coordinator

WORKSHOP IMPRESSIONS

- All sessions were held in conference rooms in New York, Manhattan, at the GHLF office building. Research coordinator, Rachael Langa at GHLF and the GHLF SMART team on this project assisted with logistics and sourcing the venue and conference space to conduct the day-long workshop.
- All sessions at the day-long workshop were conducted in a roundtable format.
- The workshop was divided into three sessions which corresponded to the three phases of research: a) The preparatory or ‘before phase of research; b) the ‘during’ phase of research; and c) the ‘after’ phase of research. All participants participated actively in the discussion.
- The workshop was conducted using a PowerPoint slide-deck presentation to assist us in maintaining focus and covering all topics on the agenda.
- Sessions included discussion questions to encourage and generate dialogue and multi-stakeholder engagement around specific topics on the agenda and to assist us in the decision-making process on what to include in the toolkit. Discussion questions were helpful to assure that all planned topics and questions were addressed.
- Participants spoke with each other during the workshop as well as directly to the facilitator and co-facilitators.
- Participants comprised five patient participants of which three had psoriatic arthritis (PsA) and two had ankylosing spondylitis (AS). Two patient leaders attended and participated, one who is an AS patient and one who is a PsA patient. Patient leaders have been active on social media as social media leaders with a large following within their disease states. We were also joined by three technical experts who included one clinical rheumatologist from the Cleveland Clinic in Ohio, Vice President of Research Programs at the National Psoriasis Foundation and Executive Director at Spondylitis Association of America (SAA), and former head of the American College of Rheumatology (ACR). Associate Executive Director of the Spondylitis Association of America (SAA), who was a technical advisor on this project and who contributed heavily to many previous discussions that led to the development of this toolkit was unable to attend this workshop. All patient participants and leaders on the project are also part of the CreakyJoints community.
- This multi-stakeholder group gave us unique insight and feedback on a draft version of the toolkit, and how this toolkit could be used in conducting research online.
- The toolkit was developed with AS and PsA as the disease states of focus and to this end much of the discussion and illustrative examples that were employed and discussed relied heavily on SpA examples. All seven patient participants had previously undertaken a three-part Research 101 Training webinar and became a CreakyJoints Patient Partner in Research (PPR) on the SMART project.

Multi-Stakeholder Social Media and Research Toolkit (SMART) Workshop

1) We identified spondyloarthritis (SpA) patients and other stakeholders who are active on social media and interested in becoming partners in research to help create a toolkit of best practices for social media engagement in health research.
2) We developed a toolkit with resources for SpA patients and clinicians interested in using social media as a platform for research engagement, and presented the draft version to our team of clinical experts, patient consultants and participants at a day-long SMART workshop.

3) We began the workshop by defining social media and highlighting some opportunities and challenges of using social media for research-related roles, activities and engagement.

4) We learned that some of the benefits of leveraging social media platforms for research included understanding questions of concern for patients (that researchers may not have considered) that may emerge in patient narratives about their experiences and management of SpA conditions, or on patient blogs and forums or through raising of directed questions on patient forums and Facebook communities.

5) For the purposes of this workshop, we focused on three social media platforms that could be used to engage patients, researchers and clinicians in all phases of research. The three platforms were Facebook, blogs and twitter.

6) Our discussion also highlighted some of the pitfalls of social media led research, which included the fact that there may be biases in sampling activities since it was suggested that patients tended to be more active when they have complaints, and that we would probably reach a select population via social media, generally attracting those who are competent online and have experience using these platforms. Some challenges were identified regarding eliciting and conducting research appropriately, and addressing issues around suitable conduct, privacy and confidentiality and the process of engagement itself. Discussion around these topics suggested that a guideline be developed to ensure no violations of privacy were at stake as much as possible. Several questions were raised about guidelines on IRB regarding social media research.

7) Our discussion around the toolkit highlighted the need to define some core values and underlying principles to scaffold our toolkit. Some of these included the following:
   - The need to uphold and adhere to ethical guidelines (to protect human subjects)
   - The commitment to facilitate research that is patient-centered and the need to foster a multi-stakeholder research environment online
   - The need to protect privacy/data security of participants
   - The need to promote relevant research and to deliver and disseminate research findings to those who can use it
   - As a pilot study, the need to develop basic and essential information for the SpA community, and include evidence based information about the pathway to diagnosis, and management and therapeutic options
   - The need to develop educational material by building a glossary to promote equitable understanding of specialized terminology
   - The need to finally scale this across disease conditions
   - The need to expand research to underserved groups
   - To need to ensure research done is patient friendly and focused

8) For the ‘before’ phase of research, our discussion centered around best practices that could be developed as part of the toolkit to guide activities online during the preparatory phase of a research project. Several best practices emerged during the workshop which will be included in the toolkit. We have mentioned some below:
   - Identifying who we are looking at – areas, diagnosis, communities
   - Identifying who you want to interact/build engagement with and creating a buzz
   - Partnering with advocacy groups that may have engaged with your target community
   - Building and sustaining trusting relationships
   - Identifying barriers – internet access, how people can participate, how many people are you missing
   - Identifying demographics of each platform, generation gaps and identifying tracking abilities for each platform
   - Practicing social listening to understand what patients are concerned about and using it as a needs assessment type of activity
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- Developing questions that are targeted and elicit responses that may serve to refine research questions and to serve in concept elicitation

9) For the ‘during’ phase of research, our discussion centered around best practices that could be developed as part of the toolkit to guide activities online during the conduct of a research project. Several best practices emerged during the workshop which will be included in the toolkit. We have mentioned some below:
  - Identifying methods to code data, identify themes, organize data using software and the manual process
  - Fostering a transparent environment and sharing information on who is funding, what the information will be used for
  - Building trust with the forums and communities we reach out to
  - Allowing for an opt out/opt in, but always with an attempt to get reasons and input on why the participant wants to opt out in the event that it should so happen
  - Getting people interested – communicating what the hook in the research project is with clarity
  - Incorporating stakeholders – including nurses and caregivers, pharmacists
  - Providing flow charts and other such aids for researchers about patient support groups

10) For the ‘after’ phase of research, our discussion centered around best practices that could be developed as part of the toolkit to guide activities around evidence based dissemination. Several best practices emerged during the workshop which will be included in the toolkit. We have mentioned some below:
  - Determining best ways to disseminate information based on which audience you may want to reach
  - Using a combination of text, images and including a “hook” or image to get attention
  - Providing a glossary of terms to both patient partners and clinician partners on the team
  - Using visuals and a combination of different formats for dissemination
  - Having an awareness of time-based understanding of your research findings—assessing what the impact of what you’re disseminating may be
  - Having a clear call to action for advocacy-related activities

11) Finally, we outlined some next steps following the workshop which included the following:
  - A refinement of the toolkit based on all the feedback and suggestions we received
  - A series on engagement calls to gain final comments once suggestions from the workshop were incorporated into the toolkit
  - The development of a short video on the SMART project for dissemination activities around SMART