



clinical trials social media

At the Crossroads of Social Media and Clinical Trials: A Workshop on the Future of Clinician, Patient and Community Engagement

June 7-8, 2018

Ruth L. Kirschstein Natcher Auditorium • NIH Campus • Bethesda, MD

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Day 1: June 7

8:00 AM Registration

8:30 AM Welcome

Jeff Abrams, MD, Associate Director, Cancer Therapy Evaluation Program, Division of Cancer Treatment and Diagnosis, National Cancer Institute

Helen Moore, PhD, Branch Chief, Biorepositories and Biospecimen Research Branch; Co-chair, Network for Direct Patient Engagement Cancer Moonshot Implementation Team, National Cancer Institute

8:45 AM

Keynote Presentation

Susannah Fox, Former Chief Technology Officer, U.S. Department of Health and Human Services

Share, Connect, Engage: Social Media as a Platform for Hope

SESSION 1: Clinical Trials Go Social – Connecting Trials to the Community

9:30 AM

Andrea Denicoff, MS, RN - Session Chair

Head, NCTN Clinical Trials Operations, Cancer Therapy Evaluation Program, Division of Cancer Treatment and Diagnosis, National Cancer Institute

Clinical Trial Accrual Challenges – Is Social Media Here to Help?



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- 9:50 AM **Luke Gelinas, PhD**, Chairperson, Advarra IRB, Senior Advisor, Multi-Regional Clinical Trials Center of Brigham and Women's Hospital and Harvard
Ethical Consideration in the Use of Social Media as an Engagement and Recruitment Tool
- 10:05 AM **Mike Fisch, MD**, Medical Director of Medical Oncology, AIM Specialty Health
Rallying Oncologists to Social Media for Clinical Trials: "Not So Fast My Friend"
- 10:20 AM Panel Discussion/Q&A
- 10:35 AM BREAK & Icebreaker
- 11:05 AM NCI's National Clinical Trials Network (NCTN) Presentations
- Thomas George, MD**, Associate Director of Clinical Investigation, University of Florida Health Cancer Center, NRG Oncology
- Jamilah Owens**, Communications Manager, Alliance for Clinical Trials in Oncology

SESSION 2: Engaging Patient Communities Online

- 11:25 AM **Janet Freeman-Daily, MS, Eng – Session Chair**
The ROS1ders
Cancer Communities on Social Media
- 11:45 PM **Gilles Frydman**, One Person Closer, Founder ACOR.org
Using Art to Help Re-humanize the Research Enterprise
- 12:00 PM **Jamie Holloway, PhD**, Clinical Research Advocate, Science 37
Overcoming Barriers to Clinical Trial Enrollment
- 12:15 PM **Nathaly Gonzalez**, Bilingual Patient Navigator/Community Outreach Coordinator, Georgetown University
Using Social Media to Increase Diversity in Research



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12:30 PM Panel Discussion/Q&A

12:45 PM LUNCH

SESSION 3: Clinician Focus – Community Building and Outreach

- 1:30 PM **Don Dizon, MD, FACP, FASCO – Session Chair**
Lifespan Cancer Institute, Rhode Island Hospital, The Warren Alpert
Medical School of Brown University
Clinicians on Social Media: A Call for Engagement
- 1:50 PM **Suzanne Millward, MPH, CHES**, Project Manager, Professional Research
Assistant, University of Colorado
*Considerations for Effective Virtual Engagement and Using Boot Camp
Translation for Improving Clinical Trial Awareness*
- 2:05 PM **Jonca Bull, MD**, Vice President, Regulatory Consulting, Global Product
Development, PPD
Diversity and Clinical Trials: Social Media – Opportunities and Challenges
- 2:20 PM **Mina S. Sedrak, MD, MS**, Assistant Professor, Department of Medical
Oncology & Therapeutics Research, City of Hope
*Engaging the Aging: Enhancing Clinical Trial Participation for Older Adults
with Cancer*
- 2:35 PM Panel Discussion/Q&A
- 2:50 PM BREAK
- 3:05 PM NCI's National Clinical Trials Network (NCTN) Presentation
- Lisa Callahan**, Communications Leader, Canadian Cancer Trials Group
(CCTG)



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SESSION 4: Innovation through Collaboration and Partnership

- 3:15 PM **Lakshmi Grama, MA, MLS – Session Chair**
Associate Director, Office of Dissemination and Digital Communications,
Office of Communications and Public Liaison, National Cancer Institute
*NCI Social Media Events and Other Opportunities for Partnering with the
Community*
- 3:35 PM **Yasmin Kloth, MS**, Senior Digital Communications strategist for NIH
AllofUs Research Program
*Connecting the Digital Dots: How to Build + Reach Online Communities
through Collaboration*
- 3:50 PM **Elizabeth Buchanan, PhD**, Endowed Chair in Ethics and Director of the
Center for Applied Ethics, University of Wisconsin-Stout
Brave New World: Social Media, Big Data, and the IRB
- 4:05 PM **David Charles, MD**, Coalition for Clinical Trials Awareness
Chief Medical Officer, Vanderbilt Neuroscience Institute
Social Media: The Future of Advocacy and Awareness Campaigns
- 4:20 PM Panel Discussion/Q&A
- 4:35 PM Closing Remarks
- Lakshmi Grama, MA, MLS**, Associate Director, Office of Dissemination
and Digital Communications, Office of Communications and Public
Liaison, National Cancer Institute



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Day 2: June 8

8:30 AM

Welcome

Emi Casas-Silva, PhD, AAAS Science and Technology Policy Fellow, Health Scientist, Biorepositories and Biospecimen Research Branch, Cancer Diagnosis Program, Division of Cancer Treatment and Diagnosis, National Cancer Institute

Sylvia Chou, PhD, MPH, Program Director, Health Communications and Informatics Research Branch, Division of Cancer Control & Population Sciences, National Cancer Institute

8:45 AM

Keynote Presentation

Sally Okun, RN, BSN, MMHS, Vice President Policy & Ethics, Human Protection Administrator, PatientsLikeMe

Social License: Empowering Partnerships across Social Media and Clinical Trials

SESSION 5: Social Media Tools and Metrics

9:30 AM

Holly Massett, PhD – Session Chair

Senior Behavioral Science Analyst, Cancer Therapy Evaluation Program, Division of Cancer Treatment and Diagnosis, National Cancer Institute

Raising Public Awareness of Clinical Trials: Tools of Engagement

9:50 AM

Jessica Schindelar, MPH, Health Communications Specialist, Centers for Disease Control and Prevention

The Health Communicator's Guide to Social Media

10:05 AM

Erin Fordyce, MS, MEd, Research Methodologist, Statistics and Methodology Department, NORC at the University of Chicago

Social Media Recruitment for Hard-to-Reach Populations: Surveying LGBTQ Youth

10:20 AM

Joshua DeLung, MA, UXC, Strategy & Quality Lead, ICF

Social Media Metrics



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10:35 AM Panel Discussion/Q&A

10:50 AM BREAK

11:05 AM NCI's National Clinical Trials Network (NCTN) Presentations

Ruth C. Carlos, MD, FACR, University of Michigan Comprehensive Cancer Center; Chair, Cancer Care Delivery Research Committee, ECOG-ACRIN Cancer Research Group

Diane M. Dragaud, MA, Director of Communications, ECOG-ACRIN Cancer Research Group

Daniel T. Woods, Operations Manager, Children's Oncology Group, COG Foundation

SESSION 6: Future Considerations

11:25 AM **Corrie Painter, PhD – Session Co-Chair**
Associated Director, Operations and Scientific Outreach, Cancer Program, Broad Institute of MIT and Harvard

Elizabeth Buchanan, PhD – Session Co-Chair
Endowed Chair in Ethics and Director of the Center for Applied Ethics, University of Wisconsin-Stout

11:30 AM **Marisa Gerstein Pineau, PhD**, Researcher, FrameWorks Institute
Messaging that Works: Framing for Understanding and Engagement

11:45 AM **Corrie Painter, PhD**, Associated Director, Operations and Scientific Outreach, Cancer Program, Broad Institute of MIT and Harvard
Count Me In, connecting patients with genomics research in the era of social media

12:00 PM **Wendy Lawton**, Communications and Public Relations Manager, SWOG Cancer Research Network, Oregon Health and Science University Knight Cancer Center
Building a Social Future for NCI Trials



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| 12:15 PM | Panel Discussion/Q&A |
| 12:30 PM | LUNCH |
| 1:15 PM | Breakout Session Prep- Please find your breakout rooms |
| 1:30 PM | Breakout Session Begins |
| 2:45 PM | Closing Remarks- Auditorium |
| | Carol Weil, JD , Program Director, Ethical and Regulatory Affairs, Cancer Diagnosis Program, Division of Cancer Treatment and Diagnosis, National Cancer Institute |
| 3:00 PM | Adjourn |