Elevating the Patient Voice

Opportunities and Challenges for Medical Writers

Thursday, November 1, 2:00-3:30 PM
American Medical Writers Association’s 2018 Medical Writing & Communication Conference

Renaissance Washington DC Downtown Hotel
Renaissance West B Room
999 9th Street NW, Washington, DC 20001
Learning Objectives

1. Identify barriers that patients face when receiving care, including making care decisions
2. Compare strategies for fostering patient engagement in care decisions and in clinical trials
3. Outline various points of the drug development process where patient experiences can be included
4. Develop content using patient-centered strategies that empower patients to be active partners in their care
Panel Discussion Sections

Engaging Patients in Care

Engaging Participants in Trials

Collaborating with Patients
Introductions

**Moderator:** Monique Pond, PhD, AAAS Science & Technology Policy Fellow

**Panelists:**
- Catina O’Leary, PhD, President & CEO at Health Literacy Media
- LaTasha Lee, PhD, MPH, Senior Manager, Partnership Engagement at American Society of Hematology
- Samir Shaikh, MBA, Deputy Director Office of Patient Affairs at FDA
1. Engaging Patients in Care
Dimensions of Patient Engagement

- Patient Satisfaction
- Informed Choice
- Shared Decisions
- Patient Partnership
- Proactive Patients
- Patient Advocate

INDIVIDUAL

COMMUNITY

Adapted from Regional Primary Care Coalition.
“[Some days] have gone very smoothly and everything is going well. And [some days] I’ve had to fight for every single thing. It seems like I’m fighting more than I’m being helped…[I want] the medical community as a whole to listen to what patients need.”

Marqus Valentine, Patient diagnosed with Sickle Cell Disease, Co-Founder of Sick Cells

All the treatments and the lack of sleep contributed to an extremely high level of fatigue I had never before experienced.

When I’m extremely tired, the pain is greater… the two are intertwined.

Patients diagnosed with Breast Cancer

“I took myself off [hydroxyurea] when I was an adult because at the time the doctors couldn’t tell me the long-term effects of taking the drug. I don't want to substitute sickle cell for another disease that I know nothing about.”

Patient with Sickle Cell Disease

2. Engaging Participants in Trials
83% patients considered potential benefits/risks of participating in a clinical trial as ‘very important’

49% participants are motivated by helping to advance science and develop treatments

53% participants report receiving no update or report after completing a trial.

Shared Decision Making
3. Collaborating with Patients
An ideal treatment would address the all-over pain, insomnia, and fatigue while also allowing clear-headed thinking and memory without fatigue or weight gain.

Patient diagnosed with fibromyalgia

Patient Input in Drug Development

Preclinical
- Patient Preferences
- Unidentified Problems
- Unmet Needs
- Product Design

Clinical
- Study Design
- Protocol Feasibility
- Informed Consent
- Summaries

Regulatory
- Benefit/Risk Analysis
- Labelling

Postmarket
- Patient-Reported Outcomes
- Benefit/Risk Analysis
- Physician Guidelines
- Patient Decision Aids

Adapted from the FDA’s Patient Preference Information Guide.
Wrap-up

- Informed patients
- Shared decision making
- Ownership of health
Resources

- PCORI: The Value of Engagement
- Dartmouth: Center for Shared Decision Making (toolkits)
- Mayo Clinic: Shared Decision Making Resource Center
- HLM’s Health Literacy in Action: Caregiver Guide
- CISCRP: 2017 Public and Patient Perceptions & Insights Study
- Amer Society Hematology: Sickle Cell Disease Coalition
- FDA: Patient Affairs Initiatives
- FDA: The Voice of the Patient Reports
- CTTI: Patient Groups & Clinical Trials
- Nature: Co-Production from Proposal to Paper
Resources