Patient Engagement Forum

Location: Marriott Washington Metro Center  
775 12th Street NW, Washington, DC 20005

Date: March 26, 2020

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| 9:00 AM | 9:10 AM| Welcome – MDIC Overview                  | Pamela Goldberg, MBA President & CEO, MDIC                          | Orientation/understanding of:  
• MDIC & Science of Patient Input (SPI)  
• Role of the organization in development of Patient Preferences (PCBR Framework)  
• Participants and roles in Forum |
| 9:10 AM | 9:20 AM| Patient Perspective                       | David Walton, Patient and Patient Advocate, Chief Executive Officer at T1D Exchange | Learn:  
• First-hand experience in regards to communicating the medical device technology received |
| 9:20 AM | 9:25 AM| Program Overview                          | Scott Goates, PhD, Boston Scientific, SPI Communications Lead      | Learn:  
• Objectives of Forum/workshop  
• What is expected from participants (based on pre-read materials) |
| 9:25 AM | 10:15 AM| Patient Panel #1: Challenges in Communicating Uncertainty and benefit/risk | Two patients with a:  
• Joint replacement  
• Spinal cord stimulator  
Two Patient Advocacy Group Representatives from:  
• Arthritis Foundation  
• American Chronic Pain Association | • Learn about patient challenges in communications from patient experts  
• Hear specific patient stories and examples of communications challenges  
• Learn from patient advocacy groups a summary of specific challenges experienced by the patient community  
• Gather a summary key issues and challenges |
<p>| 10:15 AM| 10:25 AM| Break                                    |                                                                      |                                                                                                              |</p>
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| 10:25 AM| 10:35 AM | Initial Findings from MDIC report: Best Practices for Communicating Benefit, Risk and Uncertainty | Wendy Selig, Founder & CEO at WSCollaborative LLC | Learn:  
  - Key findings of challenges and best practices of patient communications  
  - Focused introduction of key topics for input from Forum/workshop participants |
| 10:35 AM| 10:55 AM | The science of communications: Comprehension, memory, and use of medical information | Ruth Day, PhD, Director, Medical Cognition Lab, Duke University | Learn about some of the key issues identified in the science of communicating medical information  
  - Opportunity to ask questions of leading expert in field of communications and comprehension |
| 10:55 AM| 12:20 PM | Interactive Activity #1: Challenges in Communicating Uncertainty and benefit/risk | Medtronic's Innovation Lab to facilitate a guided brainstorming session among participants  
  - Karl Anderson, Director, Digital Health and Innovation Lab  
  - Tammy Lauer, Operations Manager | Participate and provide input on:  
  - key challenges in communicating difficult topics like benefit, risk and uncertainty  
  - Engage in a highly interactive brainstorming session facilitated by leaders in qualitative research  
  - Help set the agenda for focus of second part of the Forum: potential solutions |
| 12:20 PM| 1:10 PM | Lunch Keynote on Shared Decision Making (SDM)                     | J. Matthew Brennan, MD, MPH  
  Associate Professor of Medicine  
  Duke University SOM | Learn about one approach to effective communication of medical information to patients  
  - Learn how patient preferences can be incorporated into Shared Decision Making  
  - Opportunity to ask questions of leading expert in field of Shared Decision Making |
| 1:10 PM| 2:00 PM | Patient Panel #2: Best Practices in communicating uncertainty, benefit or risk and relationship to patient preferences | Two patients with a:  
  - Pacemaker  
  - Insulin pump  
  Two Patient Advocacy Group Representatives from:  
  - American Diabetes Foundation  
  - StopAfib.org | Learn about success stories in communications from patient experts  
  - Hear specific patient stories and examples of communications successes  
  - Learn from patient advocacy groups where communication has gone well in the patient community  
  - Gather a summary key successes and best practices |
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| 2:00 PM   | 3:20 PM | Interactive Activity #2: Solutions to communication challenges     | Medtronic’s Innovation Lab to facilitate a scenario development exercise among participants  
• Karl Anderson, Director, Digital Health and Innovation Lab  
• Tammy Lauer, Operations Manager | • Participate and provide input on: developing solutions for communicating difficult topics like benefit, risk and uncertainty  
• Engage in a highly interactive session facilitated by leaders in qualitative research  
• Learn how risk, benefits, and uncertainty can be communicated to patients  
• Help shape the final MDIC report as the learnings from the session will be used to further improve the best practices in the report |
| 3:20 PM   | 3:30 PM | break                                                                |                                                                    |                                                                                               |
| 3:30 PM   | 4:15 PM | Reflections on the Lessons learned and additional observations     | • Barry Liden, JD, VP of Patient Engagement, Edwards Lifesciences (Moderator)  
• Brett Hauber, Senior Economist and VP of Health Preference Assessment, RTI  
• Ruth Day, PhD, Director, Medical Cognition Lab, Duke University  
• Jodi Duckhorn, acting Deputy Director for the Office of Communication and Education, CDRH, FDA  
• J. Matthew Brennan, MD, MPH Associate Professor of Medicine Duke University  
• Heidi Dohse, professional heart patient and patient advocate, Tour de Heart | • Summarize the key findings from the event and to provide additional observations from stakeholders  
Panel Discussion:  
• Challenges and best practices in communicating benefit, risk, and uncertainty  
• How to increase interpretability  
• Facilitate patient-provider conversation  
• PPI and Labeling  
• PPI and shared decision making |
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| 4:15 PM| 4:30 PM| FDA Next Steps      | • Michelle Tarver, MD, PhD, Director of Patient Science and Engagement, CDRH, FDA  
• Alicia Witters, Acting Director, Office of Communication and Education, CDRH, FDA | • Identify key areas of opportunity for FDA to incorporate some of the lessons learned today. |