



Themes from Engagement Interviews

Interviews & Analysis

- 7 Participants: 3 stakeholders & 4 patient partners
- Interviews conducted in December and January
- Interviews lasted 10-30 minutes
 - Audio-recorded (phone or Zoom)
 - Transcribed verbatim
- 2 independent coders – BK & SL
- Deductive coding based on questions asked (i.e. barriers/facilitators to engagement, etc.)

Outline of Themes

- Previous patient/community engagement experience
- Reasons for involvement in WVDC
- WVDC Role Expectations
- Facilitators to WVDC Engagement
- Barriers to WVDC Engagement
- Suggestions to Address Barriers
- Beliefs about Impact of Engagement through WVDC and beyond

Previous Patient/Community Engagement Experience

- Primarily direct engagement with patients in education/care (not research - exception of 2 interviewees, both stakeholders)
- Patients engaged in education programs and some peer counseling/support groups
- Stakeholder experience:
 - In community coalitions and diabetes education programs
 - In one-on-one patient education
- General lack of training in patient-engaged research

Reasons for Involvement in the WV Diabetes Collaborative

- Desiring to learn more about diabetes and get more ideas for management
- Desiring to provide feedback from various perspectives to improve care, education, and resources/tools for patients
- Previous relationship with Dr. Ranjita Misra
- Personal experience and frustration with not being provided education/resources when first diagnosed → wants to help others not experience the same

Role Expectations

- Patients – to provide feedback from the patient perspective regarding the toolkit i.e. “patient sounding-board”
- Stakeholders – to provide info about resources/programs that exist and help “connect the dots” between patients and programs/providers

Facilitators to Engagement in WV Diabetes Collaborative

- General consensus with not experiencing challenges in joining meetings virtually
 - appreciation of IT (Brian Young) for assisting
- Appreciation for materials sent in advance via mail
- Welcoming environment (even in virtual setting)
- Patients and stakeholders alike describe feeling heard/respected by others
- More comfortable sharing in small breakout groups rather than the large group as a whole

Barriers to Meaningful Engagement in WV Diabetes Collaborative

- Most commonly mentioned barrier: confusion around goals of the Collaborative and toolkit (audience, purpose, and dissemination plan) for both short-term (i.e. during a meeting) and long-term (i.e. overarching project goals)
- Feelings of being unprepared – would help if there were notes/instructions included in the materials sent ahead to allow those who had time to review materials and prepare for discussion during breakout groups
- Full day for meetings can be challenging to fit in with schedule

Suggestions to Address Barriers

- Adding more time at beginning of the meeting to reorient everyone to toolkit goals, long-term collaborative goals and then go into specific goals and activities in that meeting
- Give “homework” instructions for reviewing materials before the meeting (if able) to prepare better for discussions
- Combine patient partners and stakeholders in breakout groups again and build time to get to know each other like we did at the in-person meeting

Beliefs about Impact of Engagement through WVDC and Beyond

- To inform researchers of patient concerns regarding diabetes
- Reaching hard-to-reach patient populations with diabetes care and education
- To inform and tailor programs/resources to be more useful/meaningful for patients
- To inform care practices regarding diabetes technology (e.g. continuous glucose monitoring)
- To inform marketing/communications strategies for promoting programs and existing resources to patients (including digitally and other channels considering there may be digital barriers)
- To inform patients on how to communicate with providers/advocate for themselves and get resources they need to manage their disease (not just be put on medications)