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| **Patient, caregiver and family education and support WG** |
| **Date: 10/27/16 Start Time: 9:30am CST End Time: 10:30am CST** |
| **Attendees:** Kim Schmit-Pokorny, RN, MSN, OCN, BMTCN (co-chair); Alva Roche-Green, MD (co-chair); Everett Lee; Susan Kullberg; Barry Schatz; Kate Houg (NMDP admin staff); **Not in attendance:** Jack Aiello; Margaret Bevans, RN, PhD, AOCN, FAAN; Jackie Foster, MPH, RN (lead NMDP staff), Elizabeth Murphy (NMDP staff); Evan Shereck, MD; Laura Finn, MD; Bronwen Shaw, MD; Hélène Schoemans, MD; Kristin Scheeler, LSW; Cindy Sargeant; |
| **TOPIC** | **DISCUSSION****LEADER** | **Time** | **DISCUSSION SUMMARY** |
| Welcome / Introductions | Jackie Foster | 5 min | Kate conducted roll call |
| Gather feedback on:-Themes-Gaps-Research Questions | Kim/Alva | 1. min
 | **Themes Identified**1. **Assessing the patient/caregiver to tailor education**

-Learners cultural/ethnic background-Learners Age-Role (patient/caregiver)-Whether or not the patients want to hear everything (negative information)-Patient knowledge-Caregiver knowledge-Learning style, preferred formats-Perceived risk-Health literacy-Self-efficacy-Coping styles-Readiness and ability to learn-Continuing ongoing assessments-Offering education after transplant1. **Different formats of educational materials**

-Learning styles (visual, auditory, etc)-Electronic-Print-E-tools-Videos-Web-Hands on demonstrations (training/education)-Class-Individual pieces or information all at once (timing of education)-Additional materials available-Repetitiveness of information-Retention **(overall outcome)** **-**Assessing knowldge-Individually tailored education (Name on materials?)-Methods for delivery (Timing, quantity, etc)1. **Who is providing the education**

-Healthcare provider (Nurse, pharmacist, Social worker, APP, NP/PA, homecare) - Communicating and documenting education-Transplant team-Referring physician (how much education do they receive themselves)-Patient -Peer to peer patient education-Caregiver -Who is caregiving -What is the relationship between caregiver and patient -How involved is the caregiver in patient care-Where you receive education -Exam room vs consult room -Education room -Comfort at home -Group setting -Support group -Doctor’s office vs. home setting1. **Need improved study design to improve generalizability of results**

-Studies that follow participants for a longer time-More studies with multi-center design, fewer single site pilot studies-More diversity of participants**Research questions that allow Comparative Effectiveness Research (format, timing and delivery.)****\*Overall outcome: What is going to provide the patient with the best retention?**1. Does the setting in which you receive your education make a difference in retention and understanding?
2. How effective are print educational materials compared to electronic/virtual educational materials?
3. How many patient and caregiver educational sessions are optimal
4. What is the optimal timing and frequency of patient and caregiver educational sessions? (pre-transplant, during transplant, post-transplant (acute post-transplant vs. chronic post-transplant), and long term)
5. How does lack of standardization in the patient education process affect patient and caregiver comprehension?
6. Does assessment of learner readiness (fatigue, stress, coping) improve patient and caregiver education?
7. Can educating caregivers and/or family members help with patient education?
8. Does patient-to-patient education (peer education) affect how well the information is received?
9. What are the best methods to train health professionals on patient education assessment and delivery?
10. Does training for health professional staffs on cultural competency improve patient and caregiver education?
11. What is the effect of different types of education on patient and caregiver distress?

**Include general statement:\*All of these questions should be applied at the various stages of transplant, and cannot be generalized throughout the process\***  |
| Next steps | Alva/Kim | 5 min | * Refine the research questions above
* Send out the research questions, and all participants will rank the questions in order of importance (1-5)
* Please provide additional suggestions or comments
* **Next Meeting: November 3rd, 2016**
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| Summary of tasks and next steps | Kate Houg | 5 min | Website for our working group: <https://network.bethematchclinical.org/research/research-protocols/patient-centered-research-agenda/patient--caregiver-and-family-education-and-support/> |