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| **Patient, caregiver and family education and support WG Strategy Meeting**  |
| **Date: 10/13/16 Start Time: 9:30amCST End Time: 10:30am CST** |
| **Attendees:** Kim Schmit-Pokorny, RN, MSN, OCN, BMTCN (co-chair); Alva Roche-Green, MD (co-chair); Jackie Foster, MPH, RN (lead NMDP staff), Kate Houg (NMDP admin staff) |
| **TOPIC** | **DISCUSSION****LEADER** | **Time** | **DISCUSSION SUMMARY** | **Action Items** |
| Themes  | Kim & Alva | 30 min | * **Different educational and learning preferences based on:**

-Learning styles (Visual, auditory, etc)-Learners cultural/ethnic background-Learners Age-Role (patient/caregiver)-Whether or not the patients want to hear everything (negative information)* **Different formats of educational materials**

-Electronic-Print-E-tools-Videos-Web-Additional materials available-Repetitiveness of information-Retention-Individually tailored education (Name on materials?)-Methods for delivery (Timing, quantity, etc)* **Assessing the patient/caregiver to tailor education**

-Patient knowledge-Learning style, preferred formats-Perceived risk-Health literacy-Self-efficacy-Coping styles-Readiness and ability to learn* **Communicating and documenting education**
* **Who is providing the education**

-Doctor-Patient-Caregiver* **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 |  | 5 min | 1. **Compare**
	1. **Conventional vs New**. Print educational materials versus e-tools. How effective are different strategies? Technology and mobile health as a modality for patient education? Create new tools or use tools that already exist? Do outdated tools affect how people absorb information?
	2. **Education formats**. Print, in-person, video, vs web etc. How does the design of materials influence health literacy? Technology and mobile health as a modality for patient education? Does tailoring to patient preference enhance learning, satisfaction or QOL? Does individually tailored education enhance learning? Does personalized education (for example, putting patient’s name on the materials) help patients absorb information?
	3. **Education delivery**. Timing, repetition, pacing, quantity of info, level of detail, individual vs groups etc. How many sessions to deliver education and at what point in treatment process? How many sessions to deliver education and at what point in treatment process? How much is too much? Use of a roadmap? Does variability/lack of standardization contribute to lack of knowledge? What methodology for patient education that we can compare will allow best retention of information? Retention – TCs are giving information, but they don’t remember – the delivery of information – What delivery results in best retention of information
	4. **Education by whom**. Does training on cultural competency impact patient education, learning and care? Can educating family member help education the patient? Does patient-to-patient education (peer education) impact how well the education is received?
2. **Develop, study different assessments**
	1. Develop pre-BMT needs assessment tool for individualized care for patients
	2. Assessments of learner’s attitude, coping mechanism, readiness to learn, etc
	3. Understand how stress affects how affects retention
	4. Assess learner fatigue, stress and how we use results to tailor education format, timing and delivery
3. **Training**
	1. What are best methods to train staff on patient education assessment and delivery?
4. **Secondary research questions.**
	1. Impact of education on QOL? Can lack of information aggravate distress for patients?
	2. Does higher quality education improve access to transplant?
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| Summary of tasks; next steps | Jackie  | 5 min | * Jackie will begin a draft of the documents for Symposium 2
* Kate is working on scheduling a meeting that Evan and Laura can attend to share their findings
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