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| **Patient, caregiver and family education and support WG Strategy Meeting**  |
| **Date: 10/20/16 Start Time: 10:30amCST End Time: 11:30am CST** |
| **Attendees:** Kim Schmit-Pokorny, RN, MSN, OCN, BMTCN (co-chair); Alva Roche-Green, MD (co-chair); Evan Shereck, MD; Jackie Foster, MPH, RN (lead NMDP staff), Kate Houg (NMDP admin staff) |
| **TOPIC** | **DISCUSSION****LEADER** | **Time** | **DISCUSSION SUMMARY** |
| Review of theme discussions | Kim & Alva | 30 min | * **BMT Roadmaps** -Are we giving right/sufficient information? Retention is an issue.

-Roadmaps - Give patients/caregivers an idea of where they’ve been and where they’re going – A comparative effectiveness question?-Consider possible endpoints that discuss GVHD or other complications. Includes information about management. Puts realities in front of a patient from the beginning. Often patients hear the end point they want to hear, but a road map that shows 3-4 possible paths, including GVHD or death, may help set up realistic expectations. It’s comprehensive but can be broken into pieces. -Personalized vs. generic information |
| Present themes | Evan Schereck | 10 | * **How best to provide education?** Saying something at an appointment isn’t enough. Consider what is best to help with retention and understanding. Active learning strategies (i.e. modules) are helpful and allow for repetition.
* **What’s the best educational strategy at different points in the transplant process?** Education is ongoing. Consider different info needs pre-BMT, discharge & long term.
* **Issues with studies being done with homogenous populations.** Needs to test educational strategies in diverse populations. Consider how various backgrounds (educational, cultural, financial etc.) influence teaching/learning styles.
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| Review Executive Summary draft | Kim & Alva | 15 | * **Timing of education.** Added question to draft WG Executive Summary
* **Gaps in knowledge.** Delivery includes variables such as print, electronic, and in-person (health professional to patient, patient to patient, group etc.)
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| Summary of tasks; next steps | All  | 5 | * Jackie will update documents and draft agenda
* Kim and Alva will review feedback from Laura Finn, MD and note additional gaps
* Kate will attach finalized documents/agenda to 10/27 meeting.
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