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| **Patient, caregiver and family education and support WG Strategy Meeting**  |
| **Date: 6/9/16 Start Time: 9:00am CST End Time: 10:00am CST** |
| **Attendees:** Alva Roche-Green, MD (co-chair); Kim Schmit-Pokorny, RN, MSN, OCN, BMTCN (co-chair); Hélène Schoemans, MD; Barry Schatz; Kate Houg (NMDP admin staff); Jackie Foster, MPH, RN (lead NMDP staff), **Not in attendance:** Bronwen Shaw, MD, Margaret Bevans, RN, PhD, AOCN, FAAN; |
| **TOPIC** | **DISCUSSION****LEADER** | **Time** | **DISCUSSION SUMMARY** | **Action Items** |
| Welcome / Introductions | Jackie Foster | 5 min | Jackie conducted roll call  |  |
| Literature review | All |  | * Need to find out what is already being done for research
* Key terms that we will utilize-Alva has a librarian who can do a search for the literature review using the key terms.
* **Patient education key terms**: patient education, family education, methods, research, counseling, how do patients learn, problem solving
* **Patient expectations vs. provider expectation in education**
* **General key terms**: autologous stem cell transplant, allogeneic stem cell transplant, cord blood transplant, stem cell transplant, bone marrow transplantation, family/caregiver education, palliative care, research, timing of education, survey, resources, questionnaire
* **Compare patient expectations (pre/post) to provider expectations**
* **Comprehension/expectation**
* Use both general patient/family education methods and outcomes, and then a more specific search in the HCT population
* Will look at both autologous and allogeneic transplantation
* Will then figure out how to divide up the literature
 | * Alva will contact her library on Monday to begin the literature search
* Alva will do 3 separate searches, and we will then need to weed through those articles
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| Gathering feedback from patients/caregivers | All |  | * Reach out to the patients/caregivers/support groups and ask them to identify the specific issues they see gaps to find out what their expectations are.
* Will look at doing this at the same time as the literature review
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| Summary of tasks and next steps | Kate Houg | 5 min | Schedule another meeting June 30th for the same group to get together and review the articles |  |