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| **Patient, caregiver and family education and support WG** |
| **Date: 7/7/16 Start Time: 9:30am CST End Time: 10:30am CST** |
| **Attendees:** Alva Roche-Green, MD (co-chair); Kim Schmit-Pokorny, RN, MSN, OCN, BMTCN (co-chair); Bronwen Shaw, MD; Hélène Schoemans, MD; Kristin Scheeler, LSW; Margaret Bevans, RN, PhD, AOCN, FAAN; Evan Shereck, MD; Cindy Sargeant; Everett Lee; Barry Schatz; Susan Kullberg; Kate Houg (NMDP admin staff); Jackie Foster, MPH, RN (lead NMDP staff), Elizabeth Murphy **Not in attendance:** Jack Aiello; |
| **TOPIC** | **DISCUSSION****LEADER** | **Time** | **DISCUSSION SUMMARY** | **Action Items** |
| Welcome / Introductions | Jackie Foster | 5 min | Jackie conducted roll call |  |
| Review minutes from last meeting | Jackie Foster | 5 min | * Jackie provided a review from the minutes from the 6/9/16 meeting.
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| Review sub group activities | Alva/Kim | 10 min | * We have a sub group that has met to talk about the literature reviews
* Alva had access to a medical librarian who provided article abstracts for review
* We distributed the articles to the researchers/clinicians/social workers on the group to determine if they were relevant or not
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| Discuss abstract assignments and guidelines for review | Alva/Kim | 20 min | * Kim and Alva both went through all the article abstracts, and shared them with multiple members of the sub group.
* Some articles are not relevant, some may or may not be relevant
* Recipients and caregivers on the group are welcome to review articles to their comfort level, but it is not the expectation. (Susan and Everett would like to read the caregiver articles).
* Need to come up with a review tool to identify the pertinent parts of the article for our WG. Need to determine the population, the type of article (descriptive/review), and identify gaps in knowledge and educational resources within the article
* We should stick to the transplant population, otherwise we may not see where the gaps in transplant are as clearly
* There were articles about “missing education” in certain areas. We should identify gaps in the actual content as well
* We should look at the role of technology as well (methods) and how information is given
 | * Jackie will speak with our staff to see where our WG area on support ends and where the emotional support begins
* Jackie will put together a document to assist with the literature review
* Will send out an updated table with correct responses prior to subgroup meeting
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| Discuss next steps | Alva/Kim | 15 min | * The subgroup will reconvene and review the abstract document. We will come up with the best way to divide the articles between the WG, and narrow done the list.
* Criteria:

-Population (adult vs pediatric)-Stem Cell vs Cancer vs other-Caregivers vs other-System issue vs individual factor-Comparative vs descriptive literature-Type of study. * Hope to give 5 articles to each reviewer. Will try to match article review assignments with abstract review assignments
* Helene will be on holiday until the beginning of August
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| Summary of tasks and next steps | Kate Houg | 5 min | * Next week call: Kim, Alva, Margaret, Kristin, Evan, Bronwen, Helene,
* Once we narrow down the articles, we will send them out to the reviewers
 | * Kate will send a doodle poll for a subgroup meeting
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