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| **Patient, caregiver and family education and support WG** |
| **Date: 8/4/16 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);; Hélène Schoemans, MD; Margaret Bevans, RN, PhD, AOCN, FAAN; 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; Bronwen Shaw, MD; Kristin Scheeler, LSW; Evan Shereck, MD; |
| **TOPIC** | **DISCUSSION****LEADER** | **Time** | **DISCUSSION SUMMARY** | **Action Items** |
| Welcome / Introductions | Jackie Foster | 5 min | Jackie conducted roll call |  |
| Review minutes from last meeting | Jackie | 5 min | * Jackie gave a brief review of the minutes from last month’s meeting
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| Summarize sub group activities | Alva/Kim | 10 min | * There were several phone calls with the subgroup
* We broke up the abstracts and assigned reviewers
* The reviewers summarized a bullet point for each abstract and stated whether or not it was relevant or not to our project
* We had calls to go through the abstracts and debate any abstracts where there wasn’t agreement
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| Discuss how to assign articles and review guidelines | Alva/Kim | 30 min | * We have about 50 articles to review, and were able to find full text articles of nearly all of those abstracts
* We discussed the reviewer spreadsheet with the group
* Our goal is to come up with a research agenda; so we are looking at what these articles are showing as gaps in research
* Focus on the review is more on the discussion sections of the articles, and recommendations for future research. Look at what future research questions are proposed?
* Add column to identify the primary outcome of the study, so we start to get a sense of focus of the research that is out there currently
* We will identify whether or not the article was a transplant article
* Barry, Everett, and Susan would like to look at outcome perspectives (articles related to transplant)
* There are 12 people in the group, and 50 articles. We will divide them up, and have a primary reviewer and a secondary reviewer pair for each article
* The primary reviewer will review first, secondary reviewer will briefly review article and primary reviewer’s findings. Both reviewers will meet to discuss the articles.
* Kim and Alva will look at papers that are global perspective, and the rest of the group do individual research or projects
* We will send the full text articles to the pairings that they are assigned for review
* If you run into an article that doesn’t make sense, please reach out to the group and make sure it should be included, as some of the abstracts were vague
* Our working group is focusing on patient, caregiver and family education and support. Support is a broad term, but there are other working groups covering emotional health, physical health, sexual health and financial burden. We don’t need to duplicate their work.
 | * If anyone finds themselves putting notes on the forms or thinking of other things and ways to capture that, communicate with the Co-Chairs to look at it in real time
* If you have any questions, reach out in real time and ask the questions to Kim, Alva, Jackie or Kate
* Jackie will go through articles and assign articles that would be best for the patients to review
* We will send out articles for review at the end of the day on Monday 8/8/16
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| Discuss next steps | Alva/Kim | 5 min | * Articles will be reviewed by our next meeting on September 1st
* Will have groups meet by the last week in August to discuss the articles
* Send articles to Jackie and Kate by August 29th, 2016
* Input your information into the grid and send to Jackie and Kate, and they will combine the information
 | * Kate will send out updated roster to the group
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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/> |  |