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| **Patient, caregiver and family education and support WG** |
| **Date: 5/26/16 Start Time: 9:30am End Time: 10:30am** |
| **Attendees:** Kate Houg, Jackie Foster, Kim Schmit-Pokorny, **Not in attendance:** Alva Roche-Green |
| **TOPIC** | **DISCUSSION****LEADER** | **Time** | **DISCUSSION SUMMARY** | **Action Items** |
| First call |  |  | Expand the time for the strategy discussion |  |
| Strategy Discussion | Kim |  | -Experience of patients/caregivers in this area, what would they like to have seen before, during, or after transplant. Would be good to do the brainstorming session with the entire group. -Brainstorming what can be turned into questions | -Find out what a comparative effectiveness research question would look like-See if Alva has experience with this-Find a couple of examples |
| Overarching goal | Jackie |  | Overarching goal for 2016: By November we will have a 3 page report and maybe a few summary slides that would be presented at ASH that would outline research topics specific to this topic, and that those research questions lend themselves to comparative effective research. 2017 will be flushing out the ‘how’ of how to do those. -literature review: Jackie and Kate can help with the literature review to a certain degree, as well as others on the team who have access/experience. Patients might be interested in reading some of those and including their insights. The clinicians/doctors/nurses on the team can conduct literature reviews as well.-sub groups: can meet whenever needed. Can meet additionally if nee-will be receiving a guide from Ellen to engage the patient and caregivers in the WG in our discussions and in the work.  |  |