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| **Emotional, social, and cognitive health meeting minutes** | | | | |
| **Date: May 27, 2016 Start Time: 10:30am CST End Time: 11:30am CST** | | | | |
| **Attendees:** Beattice Abetti, LCSW, Co-chair; Areej Al-Jawahiri, MD, Co-chair  Heather Jim, PhD; Cynthia Bell, RN; Anna Barata, PhD; Eneida Nemecek, MD; Jennifer Blosser, LSW; Tim Walsh, Patient; Wendy Gorrell, Patient; Rob Minton, Patient; Lizette Salazar, Caregiver; Gerardo Camarillo, Caregiver; Kate Houg (admin staff); Jill Randall, LICSW (lead staff), Ellen Denzen, MS, Linda Burns, MD  **Not in attendance:** Betsy Lucas, Patient | | | | |
| **TOPIC** | **DISCUSSION**  **LEADER** | **Time** | **DISCUSSION SUMMARY** | **Action Items** |
| Welcome/Introductions | Jill/Kate | 10 min | Jill conducted introductions for the group. Each member went through their background, and gave a brief introduction. |  |
| Overview of PCORI and project history | Ellen Denzen and Linda Burns | 10 min | The project is funded through the patient centered outcomes institute (PCORI). PCORI funds this type of research, focusing on supporting research addressing the questions, concerns, and outcomes that matter most to patients, caregivers, family members, clinicians, researchers, health program administrators (patient stakeholders).  Key component: stakeholder engagement piece. All proposals that are funded have a strong commitment to getting input from patients/patient stakeholders for the entire research project.  Overview of PCORI project was given  -2 year project  -6 working groups (including this one)  -3 symposia (first Symposium was held at Tandem in February 2016), next Symposium is at ASH in December 2016, and third at Tandem in February 2017  -4 webinars over two years |  |
| Working group goals | Areej and Beatrice | 5 min | Goals:  In our area, identify what is known about outcomes patients care about. Also, identify what is unknown (the gaps). Be prepared to recommend high priority questions |  |
| Timeline for work | Areej and Beatrice | 3 min | * 7 meetings from now until November * Summarize research area, identify gaps * Prioritize the research questions * Put together final draft for ASH   Our focus needs to include both adults and pediatrics and young adults, but should be clear on differences between pediatrics and adults.  Need to look for potential areas of overlap between this WG and the other 5 WG’s. |  |
| Strategy discussion: subgroups and literature review | Areej and Beatrice | 30 min | 6 different sub groups (adult/pediatric):   * Emotional health (anxiety, depression, psychological issues that can be affected by transplant for both the caregiver/patient) * Cognitive health (cognition, memory, ability to process, and how it affected by transplant, primary with the patient) * Social health (position of caregiver/patient within family and larger community and how that changes with a treatment like transplant/long term consequences)   Those with articles to share: Jennifer, Heather (cognitive articles), Areej (psychological/emotional articles), Anna (emotional articles) Cindy (template for evaluating, used google docs) | -Those with access to articles will share with the group  -Once articles have been identified, we will split into 6 subgroups to review the literature |
| Summary of tasks and next steps | Jill/Kate | 2 min | Those members who have compiled the literature, email to Kate and Jill. | -Figure out how to share documents (google docs?)  -email Kate and Jill any articles you have  -People volunteer to join one of the six sub groups |