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| **Patient, caregiver and family education and support WG** |
| **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); Bronwen Shaw, MD; Hélène Schoemans, MD; Kristin Scheeler, LSW; Margaret Bevans, RN, PhD, AOCN, FAAN; Cindy Sargeant; Everett Lee; Barry Schatz; Susan Kullberg; Kate Houg (NMDP admin staff); Ellen Denzen, MS (NMDP staff; working group guest); David Vanness (working group guest); Jackie Foster, MPH, RN (lead NMDP staff), Elizabeth Murphy, Jack Aiello**Not in attendance:** Evan Shereck, MD;  |
| **TOPIC** | **DISCUSSION****LEADER** | **Time** | **DISCUSSION SUMMARY** | **Action Items** |
| Welcome / Introductions | Jackie Foster | 5 min | Jackie conducted roll call, and each participant gave a brief introduction of themselves.  |  |
| Overview of PCORI and project history | Ellen Denzen | 10 min | PCORI (Patient Centered Outcomes Research Institute) is a non-profit organization, and they receive funds from the government to fund research that provides patients, caregivers and clinicians with information to make better informed healthcare decisions. As part of the project, we want to engage our stakeholders (patients, caregivers, physicians, researchers, policy makers, and program directors) in all steps of the project to gain their opinions and suggestions.As a result of Symposium 1:* Identified 6 working groups to focus on patient reported outcomes.
* Symposium 2 is going to take place in December 2016, and we will present the work that each working group has done, and receive feedback.
* Symposium 3 will be in February 2017, and we will talk about building the community we need to do the patient centered outcomes research.
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| Overview of Comparative Effectiveness Research (CER) | David Vanness, PhD | 5 min | **CER definition**: The conduct and synthesis of research comparing the benefits and harms of different interventions and strategies to prevent, diagnose, test and monitor health conditions in “real world” settings. The purpose of this research is to improve health outcomes by developing and disseminating evidence-based information to patients, clinicians, and other decision-makers, responding to their expressed needs, about which interventions are most effective for which patients under specific circumstances.* Real world treatment comparisons
* Can it work VS does it work? There are variations in patients (demographics, comorbidities, adherence), variations in treatment effects and clinical practices, and variations in what matters most to patients (PCOR)
* Works to fill an unmet need
* CER is difficult to do because of: multiple stakeholders, risk/cost, moving targets, complexity of patients, non-randomized data
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| Working group goals | Co-chairs | 5 min | The goals of this working group:* Identify gaps in the existing knowledge and literature (what is known in your focus area)
* Prioritize potential research questions that you identify. We want to make sure that the research questions selected will lend themselves to comparative effectiveness research.
* Overall goal: global manuscript of all the teams, and separate manuscripts within the working groups as information allows.
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| Timeline for work | Co-chairs | 5 min | * December 2016: written summary of activities, and short power point presentation for Symposium 2
* February 2017: Final presentation
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| Strategy discussion | Co-chairs | 25 min | Strategy:* Need to look at literature that has already been looked at, which is a good place to start.
* Will conduct literature reviews
* Talk to patients, families and caregivers about their questions and experiences
* Come up with a group of questions that can be submitted to our patient advisory groups.
* Look at existing education and support resources that already exist to identify gaps
* Look at the process in which information is given and when it is given, as patients and their families can only absorb so much information at one time
* Look into forming subgroups
* Talk with patients involved in the Peer Connect volunteer program, as they ask their peers different questions than their doctors
 | * Come up with a main strategy for information collection
* Schedule a call with a smaller group to identify the strategy
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| Summary of tasks and next steps | Kate Houg | 5 min | Schedule a call to narrow the search strategy. Outside call volunteers: * Margaret Bevans
* Alva Roche-Green
* Kim Schmit-Pokorny
* Bronwen Shaw
* Hélène Schoemans
* Barry Schatz
 | * Kate will send out a poll to schedule a outside call to discuss the strategy.
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