

Bleeding Disorder Collaborative
March 31, 2016
Meeting Minutes

7:02 a.m. **Bleeding Disorder Collaborative for Care (BDC) Convenes**

Members Present: Rebecca Kruse-Jarres, Dana Matthews, Donna Sullivan, Stephanie Simpson, Amanda Blair, Judy Felgenhauer, Mike Recht, Lisa Humphrey

Members Absent: Dan Lessler, Heidi Forrester, Michael Birmingham

Guests: Ryan Pistoresi

7:03 a.m. **Review and Discuss Medicaid Evidence-based Decisions Project (MED) Reports and Medicaid Clinical Brief**

7:03 a.m. Rebecca recaps the MED Ultrasound Report for members, focusing on the findings section. Rebecca notes ongoing studies at University of California-San Diego that are relevant to this question but are not published yet. Dana questions applying the results of a Canadian study findings to the United States. The study found that adding ultrasound cost more versus usual care in Canada which may not be true in the United States. Dana notes that ‘usual care’ in this study was radiography and not MRI and that ultrasound may be cost-savings versus ‘usual care’ in the United States with MRI. Rebecca notes that performing a longitudinal clinical trial with ultrasound would not be possible within the scope of the BDC timeline, but it may be a clinical trial in the future. Other members agree.

7:19 a.m. Rebecca recaps the MED Home Care Report for members. Rebecca notes that there are no studies of health care professionals visiting the homes of patients following medical procedures. Dana agrees with Rebecca about the lack of studies for this question. Judy suggests examining data from other chronic disease states. Dana says the idea is great but would be a challenging literature review. Members discuss how to address this topic in future clinical research.

7:25 a.m. Members review Medicaid Clinical Brief document. Stephanie recaps the document, saying the brief contains primarily opinion with little evidence on home nursing care. Mike notes that the report is incomplete with missing tables and graphs. Ryan will check with MED regarding tables and charts.

7:30 a.m. **Review and Discuss MED Research Proposal**

7:31 a.m. Ryan reviews the MED Research Proposal. Donna informs members that this research proposal is replacing the previous Key Questions from January. Rebecca notices UK Hemophilia Doctors guidelines are not included in the list of guidelines. Rebecca recommends against using the term “guidelines” for the final outcome of the BDC given the lack of evidence in certain areas. Mike agrees. Donna suggests ‘best practices’ rather than guidelines.

- 7:45 a.m. Public comments on MED Research Proposal were reviewed. First comment was to separate extended half-life products from standard half-life factors. Members agree on the recommendation, but express issues with table in general. Members ask what the purpose of the table is. Ryan explains list is from original report in January and that it was intended to encompass relevant medications in the literature review. Ryan states it may not be necessary now that the scope has changed to guidelines. Rebecca says a list of factors would be appropriate and that they do not need to be categorized like this. Additional public comments were reviewed regarding including newly approved products. Donna recommends removing brand names from list and including only types of factor as guidelines do not include brand names. Mike suggests removing table and making a simple list of “plasma derived, recombinant, recombinant extended-release, recombinant porcine”. Rebecca asks whether recombinant Von Willebrand factor is necessary. Members agree against including Von Willebrand factor. Members accept the document with proposed changes.
- 7:54 a.m. Members discuss potentially cancelling April 7 webinar since at least 2 members will be absent.
- 7:55 a.m. **Bleeding Disorder Collaborative for Care Adjourns**