

Bleeding Disorder Collaborative for Care Charter

January 11, 2016

DRAFT

COLLABORATIVE CHAIR: Rebecca Kruse-Jarres, MD, MPH

HCA SPONSOR: Dan Lessler, Chief Medical Officer

SUPPORT STAFF: TBD

MEMBERS:

Health Care Authority:

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Bleeding Disorder Centers of Excellence:

Rebecca Kruse-Jarres, MD, MPH (Washington Center for Bleeding Disorders)
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Hemophilia treatment centers:

Dana Matthews, MD (Seattle Children's Hospital) dana.matthews@seattlechildrens.org
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Judy L. Felgenhauer, MD (Sacred Heart Children's Hospital) Judy.Felgenhauer@providence.org

Others as needed with expertise to assist collaboration

AUTHORITY

Engrossed Substitute Senate Bill 6052, Chapter 4, Laws of 2015, 2015-2017 Operating Budget, Section 213, 1 (gg)(i) page 91

Overview

Purpose

To create a ***Bleeding Disorder Collaborative for Care*** tasked with identifying and developing evidence based practices related to bleeding disorders for dissemination to health care providers

Scope

As mandated by the legislature, the collaborative will 1) Identify and develop evidence-based practices to improve care to patients with bleeding disorders with specific attention to health care cost reduction, 2) Make recommendations regarding the dissemination of the evidence-based practices, and 3) Assist the Health Care Authority in the development of a cost-benefit analysis based on the evidence based practices identified.

Goals, Objectives, and Strategies

Goal

Improve care to patients with bleeding disorders

Objectives

- Identify evidence based methods to improve treatments with special attention to improving the health care quality and value;
- Create recommendations regarding the dissemination of the evidence-based practices to relevant health care professionals and support service providers; and
- Develop a cost-benefit analysis regarding the use of evidence-based practices for specific populations in state-purchased health care programs.

Strategies

- Develop new research project(s) to address gaps in existing evidence base;
- Identify methods for optimizing clotting factor use;
- Compile, analyze, and review medical evidence related to bleeding disorder treatments;
- Prioritize recommendations from thorough review of existing medical literature;
- Create Medicaid (PEB?) cost-benefit analysis based on the outputs of the Collaborative; and
- Develop practical options for incorporating identified evidence-based practices into health care treatment regimens

Authority and Milestones

Funding Authority

- HCA has the funding authority for this project. No additional funds are required.

Project Oversight Authority

- The Chair of the Bleeding Disorder Collaborative. Dan Lessler, as HCA Sponsor, will report to the HCA Executive Leadership Team as needed.

Major Milestones

Date	Topic	Documents	Outcomes	Notes
October 2015	Purpose and Scope	Budget Proviso Legislation Page 91	Agree on scope Agree on committee membership, strategies, and roles/responsibilities Identify key questions for literature review	
November/Dec 2015	Research	Information on critical gaps in research	Agree on research topics, participants, lead organization, budget allocations, & contracts	
April 2016	Review Current Guidelines and Tools	Presentation of analysis/literature review evidence-based practices to improve care to patients with bleeding disorders with specific attention to health care cost reduction	Review currently available evidence Identify evidence based practices recommendations to be included in legislative report	

June 2016 or later	Cost Benefit Analysis	Evidence based practice recommendations (agreed on by the collaborative in May)	Discussion of analysis Process for or actual ranking of guidelines and tools	
July/August 2016	Legislative Report		Receive final approval by Collaborative and complete state agency review process for legislative reports	Need to identify due date to OFM

Organization

Roles and Responsibilities

Who	Does What
Health Care Authority	<ul style="list-style-type: none"> • Provide 3 collaborative members • Help select the research projects for funding • Oversee funding streams, budgets, and contracts • Develop of a cost-benefit analysis • Report to the legislature by September 1, 2016 • Commit necessary HCA resources for the project
Bleeding Disorders Foundation of Washington	<ul style="list-style-type: none"> • Provide 3 collaborative members • Help select the research projects for funding • Oversight to guarantee the mission of this project
Bleeding Disorder Centers of Excellence	<ul style="list-style-type: none"> • Provide 2 collaborative members • Propose research to be done • Conduct research/collect data • WCBD will be the data coordinating center and assure the individual research projects stay on their timeline

Hemophilia Treatment Centers	<ul style="list-style-type: none"> • Provide 2 collaborative members • Propose research to be done • Conduct research/collect data
Chair (s)	<ul style="list-style-type: none"> • Lead collaborative meetings • Commit resources for the project • Ensure leaders of associated function commit resources for the project • Hold the Collaborative or its delegates responsible for achieving improvements • Ensure leaders of associated functions commit resources necessary to execute implementation plans
Project Manager	<ul style="list-style-type: none"> • Ensures success of collaborative meetings • Responsible for ensuring that targets and milestones are met • Develop and maintain detailed project plan and schedule • Manage all contracting obligations and oversight • Ensure clear and consistent communication within collaborative • Coordinate all stakeholders needs and expectations • Track budget expenditures • Identify and obtain needed resources (equipment, expertise, staffing, etc)
Administrative Support	<ul style="list-style-type: none"> • Coordinate meeting logistics • Ensure adherence to public meeting requirements and reasonable accommodations • Take meeting minutes/action items
Research Role 1 – WCBD?	<ul style="list-style-type: none"> • Design, organize, and manage all aspects of new research inquiry related to bleeding disorder treatment. Develop protocol and take lead for all new research data collection and analysis. Subcontracts to participating HTC?
Research Role 2 – MED?	<ul style="list-style-type: none"> • Compile and analyze existing body of evidence related to bleeding disorder treatment. Present synthesis to Bleeding Disorder Collaborative for review
Collaborative Members	<ul style="list-style-type: none"> • Attend collaborative meetings and subgroups as needed • Work together as a team to reach goals and objectives • Demonstrate respect for differing viewpoints • Support the process by asking questions and making suggestions • Volunteer for tasks to achieve continuing success in the collaborative • Assist HCA in the development of a cost-benefit analysis

Critical Success Factors (Risks)

1. Outstanding Questions:
 - Can indirects be waived? State limit on indirect costs?
 - Delegation of roles/responsibilities?
2. Adherence to open public meeting rules

3. Timelines are short and not flexible
4. Workgroup resource limitations
 - Workgroup members are not compensated
5. Recommendations for state financed health programs
 - Implementation funding not provided
 - Implementation not required by law for all payers
 - Best practice implementation requires participation of providers
 - Best practice implementation may be seen as a guideline, not a mandate

Budget

SFY16 = \$308,000 (from July 1, 2015 to June 30, 2016)

SFY17 = \$292,000 (from July 1, 2016 to June 30, 2017)

**Budget based on fiscal note, allocation dollars are flexible but required to spend in designated SFY*

Assumptions

Bleeding Disorder Collaborative for Care will not be funded beyond June 2017

Participating Organizations

Bleeding Disorders Foundation of Washington (BDFW)

Health Care Authority (HCA)

Oregon Health Science University (OHSU)

Sacred Heart Children's Hospital

Seattle Children's Hospital (SCH)

Washington Center for Bleeding Disorders (WCBD)

Revision History

VERSION	DATE	DESCRIPTION OF REVISIONS
Draft 1.0	8/11/15	
Draft 1.1	8/17/15	Addressed outstanding questions
Draft 1.2	10/7/15	Included Mike Recht's recommendations, added members and email addresses
Draft 1.3	12/29/15	Added Rebecca Kruse-Jarres as Chair Removed example budget from Budget section and provided dates for SFY16 and SFY17
Draft 1.4	1/11/16	Revised date of Cost Benefit Analysis to "June 2016 or later" under Major Milestones