

Charting Your Course Workshop Guidelines

Goal of workshop

The workshop, *Charting Your Course*, describes how information gathered at home, patient charts at Hemophilia Treatment Centres and collective Canadian data on care and treatment can contribute to the well-being of individuals and of the entire bleeding disorder community.

Target audience

- People with hemophilia or another bleeding disorder who use factor concentrates or alternatives for the management of their disease
- Parents or caregivers of a person with a bleeding disorder

Workshop format

An interactive educational session which could include one or more of the following elements:

- introductory PowerPoint presentation
- panel discussion presenting varying consumer and health care provider perspectives on patient record keeping
- information session on existing electronic data transmission systems (Advoy, DIALog, HemoNet) with optional training session

The workshop could be offered at:

- chapter family weekends
- annual general meetings
- parent support group meetings
- HTC information sessions in conjunction with clinic
- chapter/regional educational sessions

Suggested speakers and/or facilitators

- member of the Passport to Well-Being Working Group on Charting your Course (see list below)
- CHS Blood Safety Coordinator (contact dpage@hemophilia.ca)
- member of CHS Blood Safety Committee (see list below)
- CHS provincial or regional staff member
- local HTC nurse coordinator (see list on CHS website: www.hemophilia.ca)
- local HTC CHARMS Program Manager (contact HTC nurse coordinator)
- local HTC Clinic Director
- consumers representing various viewpoints
- representatives from manufacturers of factor concentrates that offer electronic data transmission systems

Passport to Well-Being Working Group on Charting Your Course

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Sample agenda

1. Opening remarks (see Sample introductory remarks below)
Chapter President or Provincial/Regional Staff
2. PowerPoint presentation (use enclosed CD and distribute copy of slides)
CHS Blood Safety Coordinator or Committee Member, HTC Nurse Coordinator, or Clinic Director or Provincial/Regional Staff
3. Interactive session (choose one or more)

Panel discussion – Issues in patient record keeping (see Suggestions for panel discussion below)

HTC Nurse coordinator, CHARMS Program Manager, parent, adults with hemophilia, etc

Or

Information Session or training on electronic data transmission systems

Representatives from manufacturers of factor concentrates in conjunction with HTC nurse coordinator

4. Evaluation of workshop (see Sample evaluation below)
5. Closing remarks (see Sample closing remarks below)
Chapter President or Provincial/Regional Staff

Sample introductory remarks

Welcome to the workshop *Charting Your Course*. The presentation is one of the modules from the new Canadian Hemophilia Society program: Passport to Well-Being designed to empower people with bleeding disorders to maximize their quality of life. Over the next year you will have the opportunity to participate in the other modules: home care, fitness and managing pain. At each session you will receive a visa stamp on your passport; collecting all four stamps will make you eligible to enter a draw for exciting prizes.

The road to well-being for a person with a bleeding disorder may have detours, roadblocks, and wrong turns. Signposts are needed to help find your way ... to chart your course. **Begin Power Point presentation** (distribute hand-out of slides for note-taking)

Suggestions for panel discussion - Issues in patient record keeping

Moderator

- CHS Blood Safety Coordinator
- A member of CHS Blood Safety Committee
- CHS provincial or regional staff member

Panel members

- An adult with a bleeding disorder
- A parent of a child with a bleeding disorder
- A teenager with a bleeding disorder
- A member of the CHS Blood Safety Committee
- A local HTC director
- A local HTC nurse coordinator

Suggested discussion topics

- The benefits of good record-keeping
- The consequences of not providing accurate, timely patient records
- The need for timely feedback from the staff at the HTC
- Concerns over confidentiality of medical information
- The reporting of adverse reactions – what, when and how

Sample closing remarks

- thank speakers and participants for attending
- collect evaluations
- hand out - Charting Your Course Booklet
- invite participants to pick up a passport and have it stamped with the Charting Visa at the Passport to Well-Being Booth (if not available, set up a table for this)

Evaluation of Charting Your Course Workshop

1. **The format of this workshop involved a PowerPoint presentation followed by interactive sessions regarding patient record keeping. How would you rate the effectiveness of this format?**

1	2	3	4	5
Poor	Fair	Average	Good	Excellent

2. **To what degree did the information presented at this workshop provide you with :**

- a) New knowledge or better understanding of the benefits of patient record keeping.
Not at all somewhat much very much
- b) New knowledge or better understanding of methods of reporting patient home care information.
Not at all somewhat much very much
- c) New knowledge or better understanding about CHARMS, the Canadian Hemophilia Registry, and Centre Point.
Not at all somewhat much very much
- d) New knowledge or better understanding of the existing surveillance-notification systems in place in Canada.
Not at all somewhat much very much

3. **Comments or suggestions for future workshops on this topic.**

4. **Please indicate your role within the bleeding disorder community:**

a) person with hemophilia - f VIII deficiency _____ f IX deficiency _____

b) person with von Willebrand Disease _____ Type _____

Other
c) parent/caregiver of a person with hemophilia or VWD _____

d) HTC health care professional – nurse _____ clinic director _____ other _____

e) CHS staff – national _____ provincial _____ regional _____