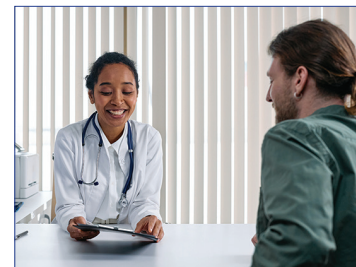


WFH Shared Decision-Making Tool



Suzanne O'Callaghan

In these times of new therapies, how does the global bleeding disorders community best approach treatment and care?

The **World Federation of Haemophilia (WFH) 2023 Global Policy and Advocacy Summit** was conducted virtually in July 2023 and was a great opportunity to reflect on some of the issues from an international perspective.

Plenary: Shared decision-making model in healthcare

Chair ~ Courtney Thornburg, Medical Director, Hemophilia and Thrombosis Treatment Center at Rady Children's Hospital, San Diego, USA

Speakers: Mark Skinner, WFH Executive Committee; President, WFH USA; Donna Coffin, WFH, Canada; Victor Jiménez-Yuste, HTC Director, Spain; Bradley Rayner, GNMO, South Africa

With the variety of new haemophilia therapies now available and coming to market, people with haemophilia need to consider their treatment options carefully and understand what is right for them. Informed decision-making is crucial to this.

The Summit provided a platform to launch the new **WFH Shared Decision-Making tool for hemophilia**.

Mark Skinner explained the Shared Decision Making (SDM) process, where clinicians and people with haemophilia work together to make decisions about treatment.

This process is patient-centred and helps them to personalise the decision-making to the individual: taking into account both the clinical outcomes that are likely, such as reduced number of bleeds, and also the patient's personal goals, such as no limits on work, school, family life. This process would be repeated at times over the patient's lifetime and as their treatment choices and life goals evolve. It is also a process that makes the patient a full partner in their healthcare team.

What is the Shared Decision Making process?

- A patient shares with a clinician all their aspirations, relevant preferences, values and goals
- A clinician shares with a patient all relevant information and best scientific evidence available on all the pros and cons of all potential treatment options
- With this mutual understanding, the patient and the clinician decide the best course of action.

The WFH Shared Decision-Making Tool is an interactive aid for decision-making designed to facilitate discussions about treatment options between people with haemophilia and or parents/carers and their healthcare team. It is intended for discussions about prophylaxis treatment and takes a step-by-step approach to questions such as:

- What are my goals? How is my current treatment limiting my goals?
- What are my treatment options? What are the benefits and risks, potential side effects?
- Who else do I want to talk to about the treatment options?
- Who else do I want involved in my decision?

The tool includes information about a range of haemophilia treatments available and innovative interactive tables for patients to compare their options, including lifestyle impact. The patient can write their reflections, preferences and questions in the online tool and download a PDF of their personalized summary to help the discussion with their healthcare team.

The Tool is available on the WFH website – www.wfh.org.

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