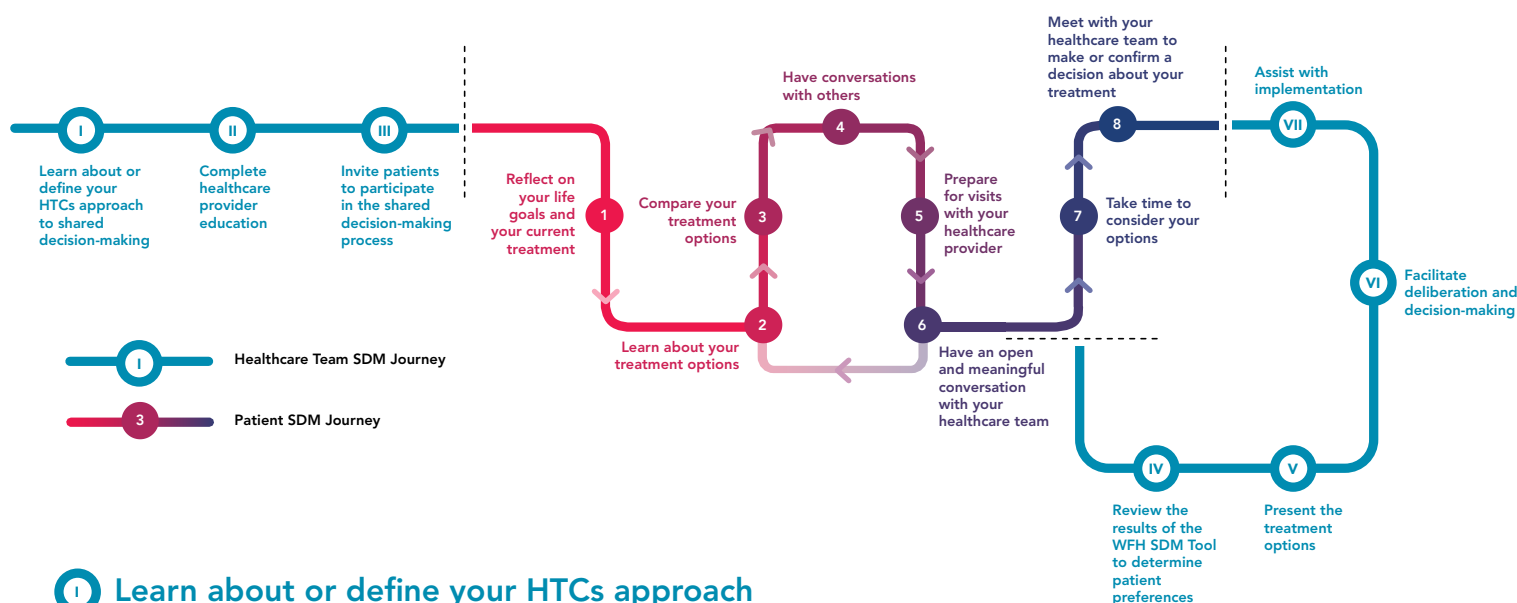




THE ROLE OF THE HEALTHCARE TEAM IN SHARED DECISION-MAKING

This document is a guideline for healthcare teams engaging in shared decision-making with a person with hemophilia while using the WFH Shared Decision-Making (SDM) Tool. The WFH SDM Tool was designed to guide and support people with hemophilia A or B and their caregivers in gathering information to facilitate more meaningful and collaborative discussions with their healthcare team. Patients are provided with an 8-step guide to shared-decision making with the WFH SDM Tool; this is the accompanying 7-step guide for health care teams. The WFH SDM Tool will be updated periodically as new treatments or information become available.



I Learn about or define your HTC's approach to shared decision-making

- How are patients identified?
- Who will be included in the discussions? Physicians, other key clinicians, nurses, social workers, genetic counselors, and more could participate in these discussions.
- When and how will discussions occur? How much time should be scheduled? Virtual vs. in-person visits?
- How will the discussions be documented?

II Complete healthcare provider education

- There are many educational materials available for shared decision-making. Please see the [educational resources for the healthcare team](#) page for more information.

III Invite patients to participate in the shared decision-making process

- Explain SDM, gauge patient interest, review what the patient already knows, and suggest using the WFH SDM Tool. Be sure to review the **Potential Decision Outcomes** (Box 1).
- Inform patients of what treatments they might be eligible for now or in the future.
- Provide an opportunity to involve trusted others in the decision process.

IV Review the results of the WFH SDM Tool to determine patient preferences

- Use past conversations and the personalized summary report from the WFH SDM Tool to facilitate an informed discussion of the patient's life goals and preferences and how they relate to their treatment options. This report will include responses to open-response **Questions for Reflection** (Box 2), ranked **Statements for Reflection** (Box 3), and patient-selected treatment options.

V Present the treatment options

- Provide 2–4 treatment options based on the patient's interests, eligibility, and the available evidence.
- Review the efficacy, safety, benefits, and risks of each treatment option. What will be involved in the treatment process and follow-up period? How will the treatment impact mental health and quality of life? How might the treatment impact the patient's life goals?
- Encourage the patient to take the time they need to consider their options.

VI Facilitate deliberation and decision-making

- What is the patient leaning towards? Are there any barriers to making a decision?
- If a patient has an informed and clear preference, support implementation.
- If a patient defers to your recommendation, check your common understanding, and identify any concerns before implementation.
- If a patient is not ready to make a decision, identify the barriers (e.g., information, lack of support, unclear/conflicting priorities, needs more time to consider, etc.) to making a decision and create a plan to address them. Support continued reflection and deliberation.

VII Assist with implementation

- Eligibility screening, insurance queries, scheduling, etc.

BOX 1. POTENTIAL DECISION OUTCOMES

- Remain on the current treatment
- Modify the current treatment
- Change to a new treatment
- Continue education and follow-up discussions

BOX 2. QUESTIONS FOR REFLECTION

Patients may provide written answers to these questions.

- How would you describe the impact of your hemophilia on obtaining your life goals? (Goals related to work, education, family, hobbies, etc.)
- Why are you considering a change to your therapy?

BOX 3. STATEMENTS FOR REFLECTION

Patients are asked to rank these statements on a scale of 0 (not at all) to 100 (very much)

- I feel tied to (or constrained by) my hemophilia treatment regimen.
- Managing my hemophilia takes a lot of effort.
- My hemophilia is always in the back of my mind.
- I feel adequately protected against bleeds.
- I am concerned about the potential side effects of novel therapies for hemophilia.
- I feel upset about missing significant opportunities because of my hemophilia.
- My hemophilia makes it difficult to keep up a satisfying social life.
- My hemophilia keeps me from being able to fulfill the roles I expect to be able to do.