



NATIONAL HEMOPHILIA FOUNDATION
for all bleeding disorders

HEALTH EQUITY THROUGH HTC_s

HEALTHCARE PROVIDER TOOL KIT

RESOURCES FOR YOUR PRACTICE

- 1** SOCIAL DETERMINANTS OF HEALTH
- 2** SHARED DECISION MAKING
- 3** GIVING AND RECEIVING FEEDBACK



ABOUT THIS RESOURCE

ABOUT NHF

The **National Hemophilia Foundation (NHF)** is dedicated to finding cures for inheritable blood disorders and to addressing and preventing the complications of these disorders through research, education, and advocacy enabling people and families to thrive.

ABOUT THIS INITIATIVE

This mission to address and prevent complications of all bleeding disorders drives NHF's work to better understand health disparities and develop interventions that can begin to address those differences and promote health equity. NHF's Enhancing Health Equity Through Hemophilia Treatment Centers is an education intervention research program designed to **gather insight into Black/African-American patient experiences in order to strengthen HTC's ability to reduce health disparities, increase equity in access to quality care delivery for underserved patients, and address social factors that may impede a patient's ability to manage their health, engage in care and adhere to treatment.** Through focus groups and interviews of Black/African-American patients and caregivers, as well as healthcare providers and staff at 2 HTCs, NHF developed the following resources for healthcare providers to have available for reference in their offices for ongoing self-reflection and learning.

ABOUT THESE TOOLS

The following pages are meant to act as a visual reminder to keep health equity top of mind when working with patients. You can think of it as a checklist of sorts. While it wouldn't necessarily make sense to ask every single question below to each individual patient, placing this where you see it often may help you cue into patients overall needs and aid as a reminder to ask pertinent questions as needed. These will also act as reminders for self-reflection in your own practice.

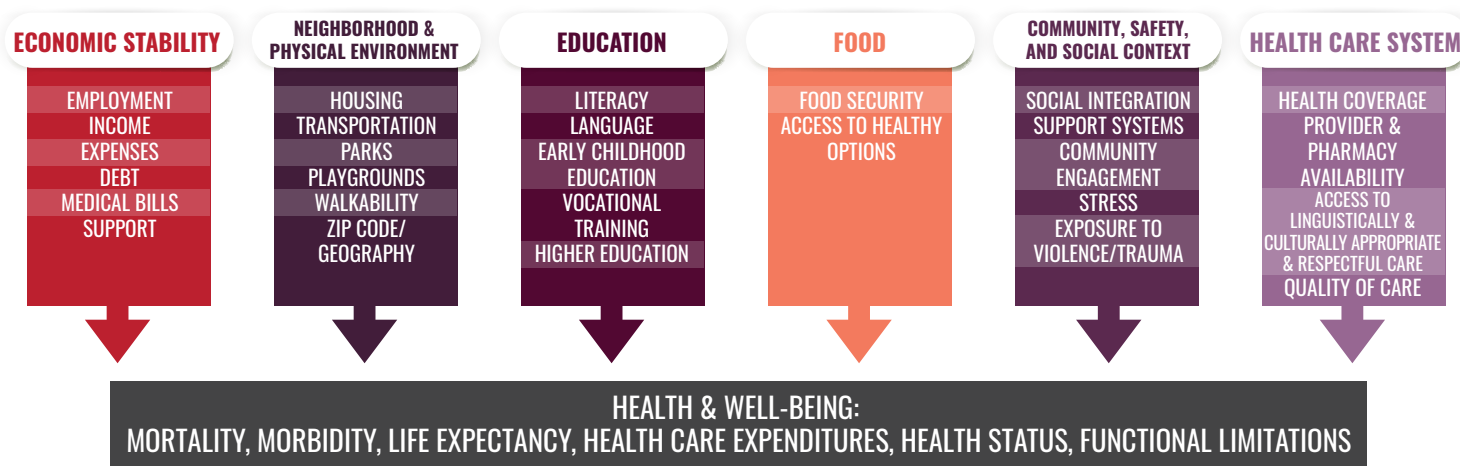
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SOCIAL DETERMINANTS OF HEALTH

Only 20% of a person's overall health is determined by their actual healthcare. The remaining 80% is determined by other factors – social determinants of health. Social determinants of health (SDOH) are the conditions in the environments, where people are born, live, learn, work, play, worship, and age that affect a wide range of health, functioning, and quality-of-life outcomes and risks, as demonstrated in this table from the Kaiser Family Foundation.



QUESTIONS TO THINK ABOUT

1 - DID YOU ACCOUNT FOR YOUR PATIENT'S ECONOMIC STABILITY?

- Can they afford their treatment?
- Does your patient have health insurance? Do they know how to access services?
- Will lifestyle/working hours interfere with established treatment plan?

2 - DID YOU ACCOUNT FOR YOUR PATIENT'S NEIGHBORHOOD AND PHYSICAL ENVIRONMENT?

- Does the patient have a stable living situation? Do they feel safe in their neighborhood?
- Does the patient have access to easy and affordable transportation to the HTC?
- Are the opportunities for exercise or physical activity, which can be accessed in a safe and affordable way?

3 - DID YOU ACCOUNT FOR YOUR PATIENT'S LEVEL OF EDUCATION?

- Did you give your patient ample opportunity to ask questions?
- Was the length of the appointment sufficient to educate the patient according to their needs?
- If the patient doesn't speak English, was a translator made available to help facilitate communication?
- Was the information you discussed with your patient in simple, plain language to meet them at their health literacy level?

4 - DID YOU ACCOUNT FOR YOUR PATIENT'S ACCESS TO FOOD?

- Does the patient have access to affordable fresh produce and groceries?
- Does your patient know the impacts of gaining weight or other comorbidities when they already have a bleeding disorder diagnosis?

5 - DID YOU ACCOUNT FOR YOUR PATIENT'S COMMUNITY, SAFETY, AND SOCIAL CONTEXT?

- Did you account for your patient's current lifestyle in relation to their community and culture?
- Does your patient have a support network on which they can rely? If so, are they integrated into the treatment plan?
- Are there any psycho-social issues which need attention, or will be prohibitive to following a treatment plan?
- Is the patient connected with their local chapter, resources, and the broader bleeding disorders community?

6 - DID YOU ACCOUNT FOR HOW YOUR PATIENT INTERACTS WITH THE HEALTHCARE SYSTEM?

- Does your patient use the same methods of communication as the HTC to connect?
- Does your patient feel like they are allowed to be themselves when interacting with care providers?
- Does your patient receive the same quality of care as other patients you see?



RESOURCES TO LEARN MORE

U.S. Department of Health and Human Services. (2022). Social Determinants of Health Literature Summaries. Healthy People 2030.

<https://health.gov/healthypeople/priority-areas/social-determinants-health/literature-summaries>

Thomas-Henkel, C. & Schulman, M. (2017). Screening for Social Determinants of Health in Populations with Complex Needs: Implementation Considerations. Center for Health Care Strategies, Inc. (CHCS).

<https://www.chcs.org/media/SDOH-Complex-Care-Screening-Brief-102617.pdf>

The EveryONE Project Social Determinants of Health Guide to Social Needs Screening. (2019). Social Determinants of Health Guide to Social Needs Screening. American Academy of Family Physicians.

https://www.aafp.org/dam/AAFP/documents/patient_care/everyone_project/hops19-physician-guide-sdoh.pdf

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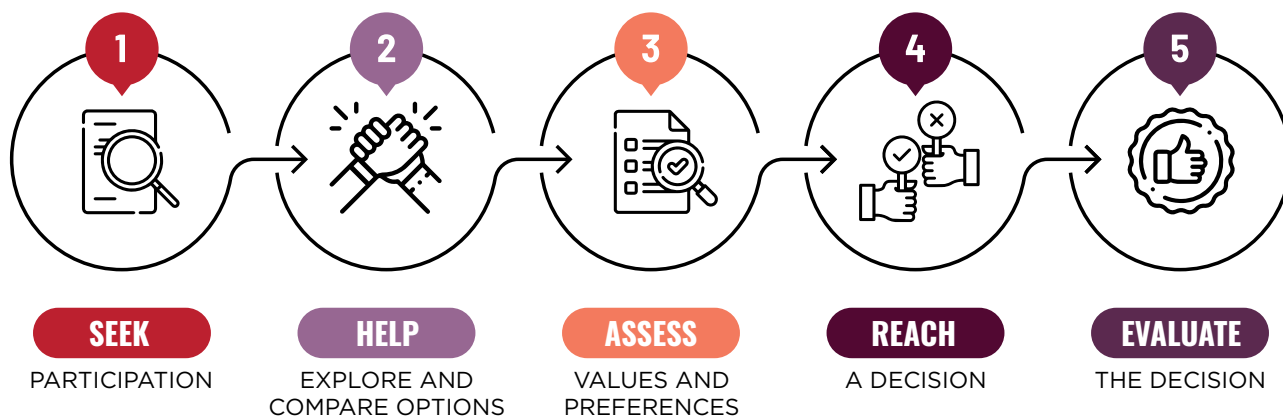
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<https://www.kff.org/coronavirus-covid-19/issue-brief/tracking-social-determinants-of-health-during-the-covid-19-pandemic/>



SHARED DECISION MAKING

The **SHARE** Approach presents a **five-step process** for shared decision making that includes exploring and comparing the benefits, harms, and risks of each option through meaningful dialogue about what matters most to the patient. This model encourages a holistic approach, including the patient along with their overall lifestyle and personal values as a part of the conversation while working together to create a treatment plan or address their other challenges in order to best support their overall health.



QUESTIONS TO THINK ABOUT BEFORE YOUR PATIENT VISITS AND REVIEW AFTER

STEP 1 - SEEK YOUR PATIENT'S PARTICIPATION

- Did you ask your patient(s) why they came to the clinic today, or if there is any specific issue that needs resolution before the end of the appointment?

STEP 2 - HELP YOUR PATIENT EXPLORE AND COMPARE OPTIONS

- Did you present all of the available options to your patient?
- Did you discuss the benefits and risks of each option to the point that the patient understands and is able to make an educated decision?
- Did you ask the patient if they have any questions about any of the options?

STEP 3 - ASSESS YOUR PATIENT'S VALUES AND PREFERENCES

- Did you ask your patient what decision-making factors matter most to them?
- Did you acknowledge the values and preferences of your patient?
- Did you show empathy for your patient as you hear about their experiences?

STEP 4 - REACH A DECISION WITH YOUR PATIENT

- Did you ask the patient which option they prefer?
- Did your patient participate in coming to a final decision?
- Did you ask your patient if they would like any additional educational materials to help make the decision?
- Did you ask your patient if they need more time to make a decision?

STEP 5 - EVALUATE YOUR PATIENT'S DECISION

- Did you follow-up with the patient to see if the solution is working as discussed?
- Did you follow-up with the patient to see if the treatment plan is working with their lifestyle?
- Did you assist your patient with managing barriers to implementing their decision?



RESOURCES TO LEARN MORE

International Patient Decision Aid Standards (IPDAS) Collaboration.
<http://ipdas.ohri.ca/index.html>

Mayo Clinic Shared Decision Making National Resource Center.
<https://carethatfits.org/shared-decision-making/>

REFERENCES

The SHARE Approach—Essential Steps of Shared Decision making: Quick Reference Guide.
Agency for Healthcare Research and Quality, Rockville, MD.
<https://www.ahrq.gov/health-literacy/professional-training/shared-decision/tools/resource-1.html>

Valentino LA, Blanchette V, Negrier C, O'Mahoney B, Bias V, Sannie, Skinner MW. (2021). Personalising haemophilia management with shared decision making. *J Haem Pract*, 8(1): 66-76.
<https://sciendo.com/article/10.17225/jhp00178>



GIVING AND RECEIVING FEEDBACK

Giving and receiving feedback well is important for building trust, be it with a patient to ensure you are aware of and supporting their needs, or with a colleague to work together to improve patients' experiences and outcomes. These are skills which can be learned and then exercised just like a muscle. It can feel uncomfortable to give feedback you think the person may not want to hear. On the reverse, oftentimes when feedback is given, it is a common human response to become defensive to this information and reject it as false without doing due diligence. Here are some tips to make those conversations as successful as possible.

TIP 1: CONSIDER THAT WE ALL HAVE BLINDSPOTS

A blindspot is something we don't see about ourselves that others do see, which is demonstrated in this model called the Johari Window, developed by psychologists Joseph Luft and Harry Ingham. There are also blindspots when it comes to knowledge. Any knowledge, which is unknown by you, but is known by others constitutes a blindspot. When interacting with others, these blindspots may cause reactions for us and we don't even realize it. It could lead you to changing the topic to how you feel instead of continuing to listen and address the other person(s) in the conversation.

	KNOWN BY SELF	UNKNOWN BY SELF
KNOWN TO OTHERS	PUBLIC	BLINDSPOT
UNKNOWN TO OTHERS	PRIVATE	UNKNOWN

TIP 2: REFLECT ON WHAT TRIGGERED YOUR RESPONSE

Understanding what about the conversation or feedback made you feel or act that way is important to helping guide the discussion back or work toward a better interaction in the future. Start by listening to your internal voice and how it was responding. The table below, from *Thanks for the feedback: The science and art of receiving feedback well*, by Douglas Stone and Sheila Heen, can serve as a directional compass for this emotional data, so you can then ask further questions of that person to better understand their perspective.

INTERNAL VOICE	LISTENING FOR	QUESTIONS TO ASK
<p>TRUTH</p> <p>That's wrong! That's not helpful! That's not me!</p>	<p>Data they have that I don't, and interpretations they have that aren't the same as mine.</p> <p>Impacts I'm having that I may not be aware of because of my blind spots.</p>	<p>Can you give me an example? What did that mean to you? What are you worried about? What do you see me doing that's getting in my own way? How did that impact you?</p>
<p>RELATIONSHIP</p> <p>After all I've done for you?! Who are you to say? You're the problem, not me.</p>	<p>Switchtracts that put a second topic on the table about our relationship.</p> <p>Systems between us — what are each of us contributing to the issues, and what's my part in that system?</p>	<p>Help me understand your feedback. Then I want to talk about how/when/why you're offering it and some of my relationship concerns.</p> <p>What am I contributing to the problem between us? What is the most upsetting to you and why?</p>
<p>IDENTITY</p> <p>I screw up everything. I'm doomed. I'm not a bad person — am i?</p>	<p>Can I sort for Coaching, focused on the opportunity to grow, rather than the judgment implicit in the evaluation or coaching?</p>	<p>Can you help me get perspective on your feedback? What could I do that would help me improve? What could I change that would matter most?</p>



GIVING AND RECEIVING FEEDBACK

QUESTIONS TO ASK YOURSELF

Ask yourself these questions as you prepare to **GIVE** feedback

1 - MAKE THE FEEDBACK OBJECTIVE

- Are you prepared to describe the issue at hand without passing judgment
- Will the person receiving your feedback feel targeted by what you plan to share?
- Does the feedback you've prepared include comments with clear takeaways rather than beating around the bush?
- Does your feedback include recent, specific real-life examples which clearly communicate the issue?

2 - BALANCE THE GOOD AND BAD

- Did you include positive feedback along with the constructive feedback?
- Did you offer to help, in the case that their weakness is one of your strengths?

3 - ASK, DON'T ASSUME

- What questions do you plan to ask to gain a more clear understanding of the situation?
- Are you prepared to answer questions as you collaborate with others to solve the issue?

4 - PERSONALIZE THE FEEDBACK

- Did you consider the personality of the recipient for your feedback and tone?
- Did you tailor your feedback according to how the recipient prefers to be approached?
- Do you know what motivates the recipient, and can include talking points referencing this motivation to create a more collaborative and empathetic discussion?

5 - PREPARE AHEAD

- Did you prepare your feedback in advance, giving yourself a chance to think through what you want to share and how the feedback may be received?
- Do you have talking points prepared, an agenda created, or are otherwise prepared to maintain the flow of conversation for giving feedback?
- If the feedback is concerning an especially sore subject, are you prepared to be considerate in how you communicate, and offer the recipient support and guidance if necessary?

6 - TIMING MATTERS

- How will the timing in which the feedback is given affect the overall situation?
- Is there an opportunity to incorporate the feedback into a format or time in which feedback will be expected by the recipient?
- Are you addressing the issue in a timely manner without letting negative emotions or underlying issues fester to cause a larger problem in the future?
- Transport yourself one year into the future - will the feedback you're giving now have a positive effect on the future of your collaboration?

You may want feedback from your patients or your colleagues, so when you **RECEIVE** feedback, here's how to increase your chances of hearing the truth

SHARE THAT YOU WANT HONEST FEEDBACK

- Did you let others know that you want honest feedback?
- Did you ask for helpful, constructive, feedback - even if it's 'not nice?'

FOCUS ON THE FUTURE

- Rather than getting stuck in the past only, did you ask what you could improve on moving forward?

PROBE DEEPLY

- Did you ask for feedback more than once to ensure those you're asking really know what you are looking for?
- Did you ask for more information regarding specific situations where the feedback may be most applicable?

LISTEN WITHOUT JUDGMENT

- Did you listen to the feedback without judgment or becoming defensive?
- Did you thank the person giving you feedback for the honesty in their observations and opinions?

PAUSE AND ABSORB

- While receiving feedback, did you write down what was said?
- Did you pause at various points throughout the conversation to really take in what is being said?
- Did you give sufficient time for the person providing feedback to fully share their thoughts - including pauses between sentences for contemplation?



RESOURCES TO LEARN MORE

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<https://www.skillpacks.com/how-to-request-feedback-from-coworkers/>

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<https://hbr.org/2014/12/how-to-ask-for-feedback-that-will-actually-help-you>

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<https://360learning.com/blog/tips-effective-peer-feedback-loop>