

Patient Decision Making in Hematologic Malignancies

Learning Objectives

- Differentiate between clinical centric and shared patient decision making
- Understand the mutual benefits of shared patient decision making for patients with hematologic malignancies and HCPs
- Identify potential barriers to shared patient decision making and be able to propose solutions

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SUMMARY

All hyperlinks are functional in slide show mode.
MCL, mantle cell lymphoma.





CHAPTER 1: What Is Patient Decision Making in Hematologic Malignancies?



Shared Decision Making Between HCPs and Patients

- Shared patient decision making occurs when an HCP and a patient work together to make a healthcare decision that is in the best interest of the patient¹⁻³
 - An optimal decision stems from meaningful dialogue to compare benefits and risks
 - This type of decision making takes into account evidence-based information, the HCP’s knowledge and experience, and the patient’s values and preferences

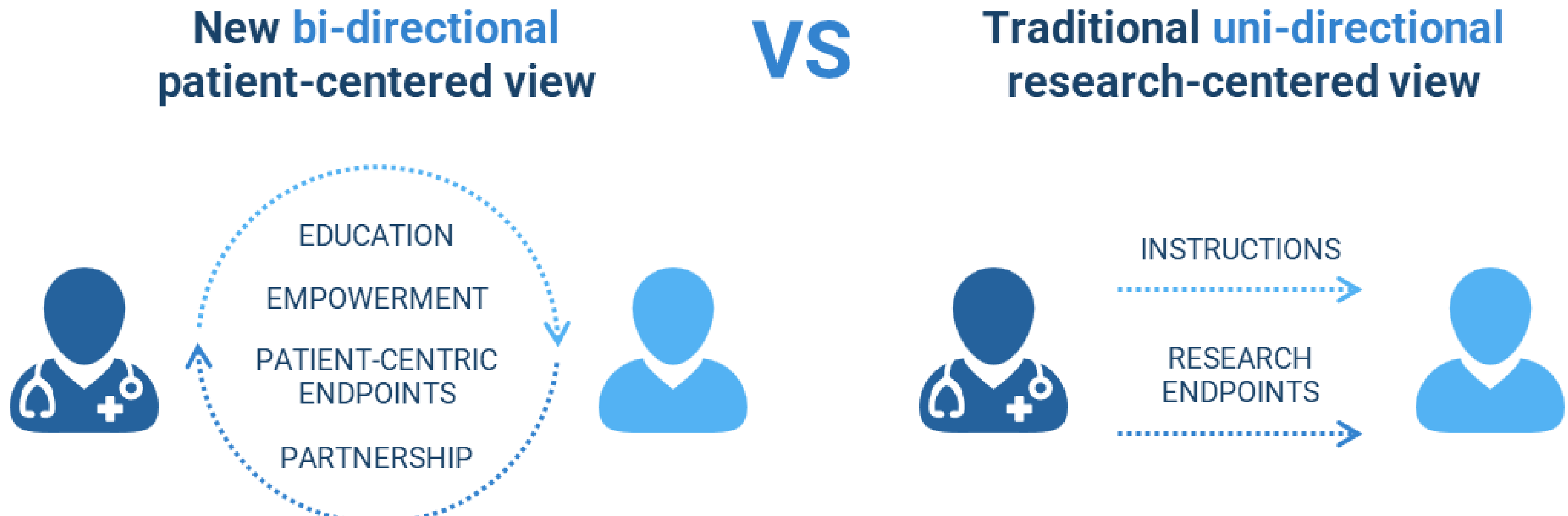


Image adapted from: LUNgevity Transforming Lung Cancer. Accessed August 3, 2023. <https://www.lungevity.org/research/patient-focused-research-center-patient-force/shared-decision-making>.

HCP, healthcare provider.

1. Katz SJ, et al. *J Oncol Pract.* 2014;10(3):206-208. 2. Brown R, et al. *J Clin Oncol.* 2012;30(8):857-862. 3. Agency for Healthcare Research and Quality. Accessed July 28, 2023. https://www.ahrq.gov/sites/default/files/publications/files/share-approach_factsheet.pdf.

Clear Communication and Expectations in Shared Decision Making

- Shared decision making starts with optimal communication to help with the following
 - Supporting patients with their emotions and understanding of medical information
 - Allowing for better identification of a patient's goals and preferences
 - Setting expectations so patients are aware that the decision making process can be complex, with varying levels of evidence-based criteria

New bi-directional patient-centered view

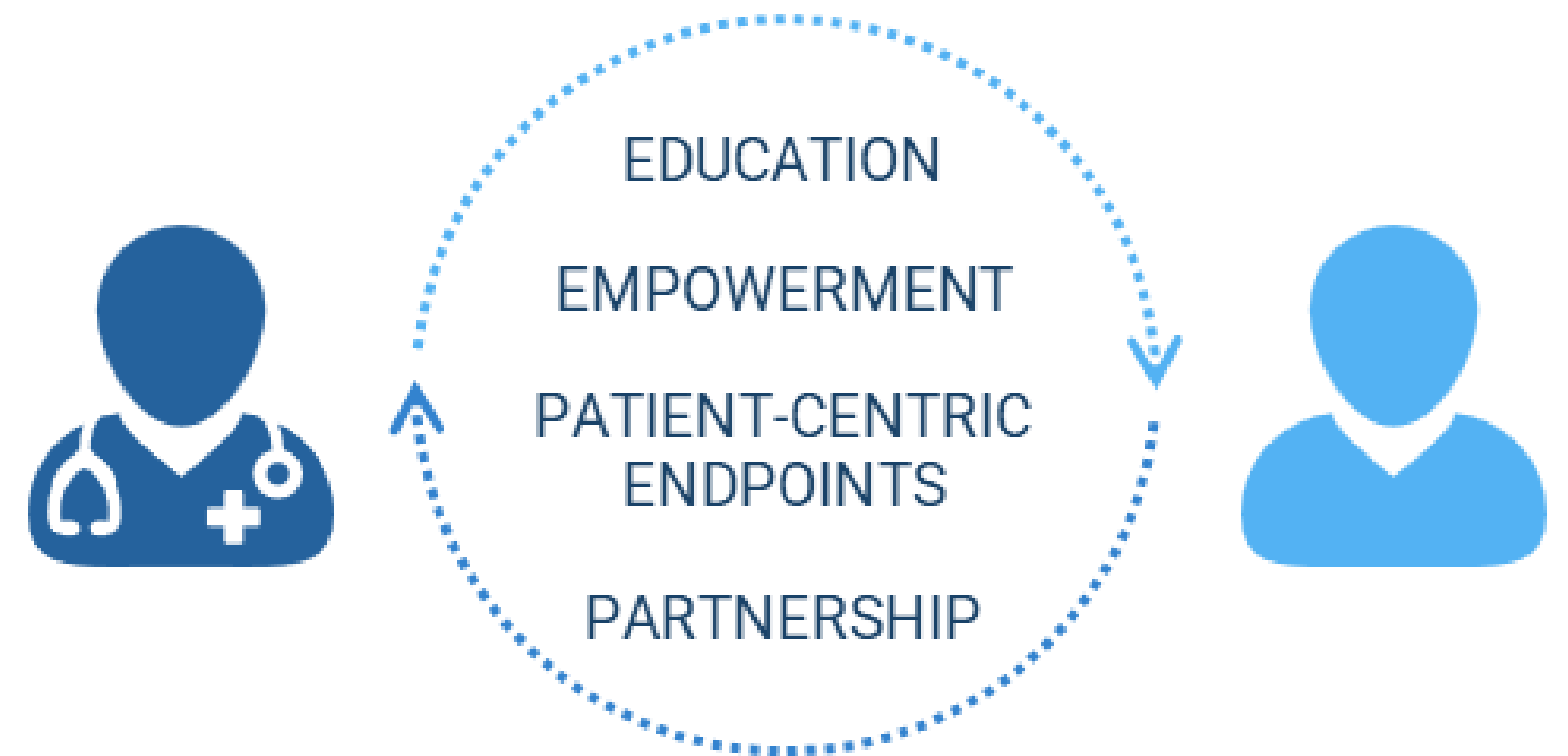


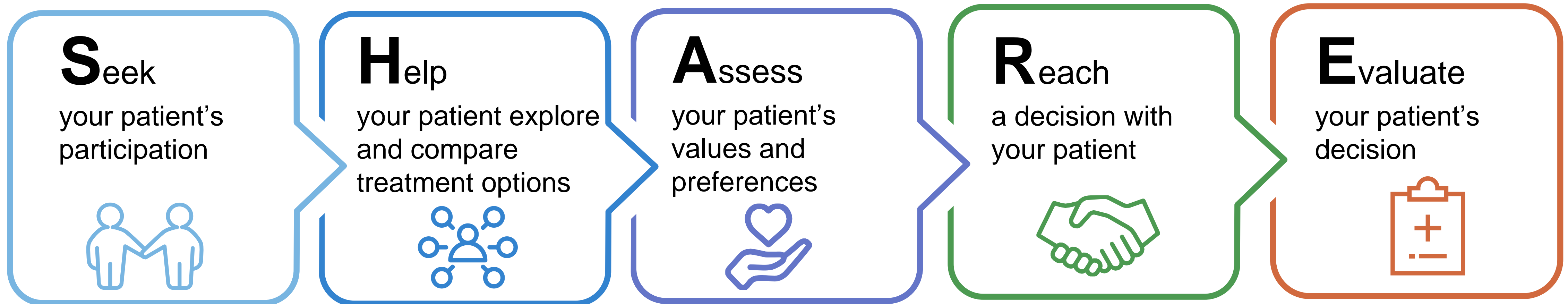
Image adapted from: LUNgevity Transforming Lung Cancer. Accessed August 3, 2023. <https://www.lungevity.org/research/patient-focused-research-center-patient-force/shared-decision-making>.

Structured approaches to decision making help set patients' expectations and provide objective parameters for the decision making process



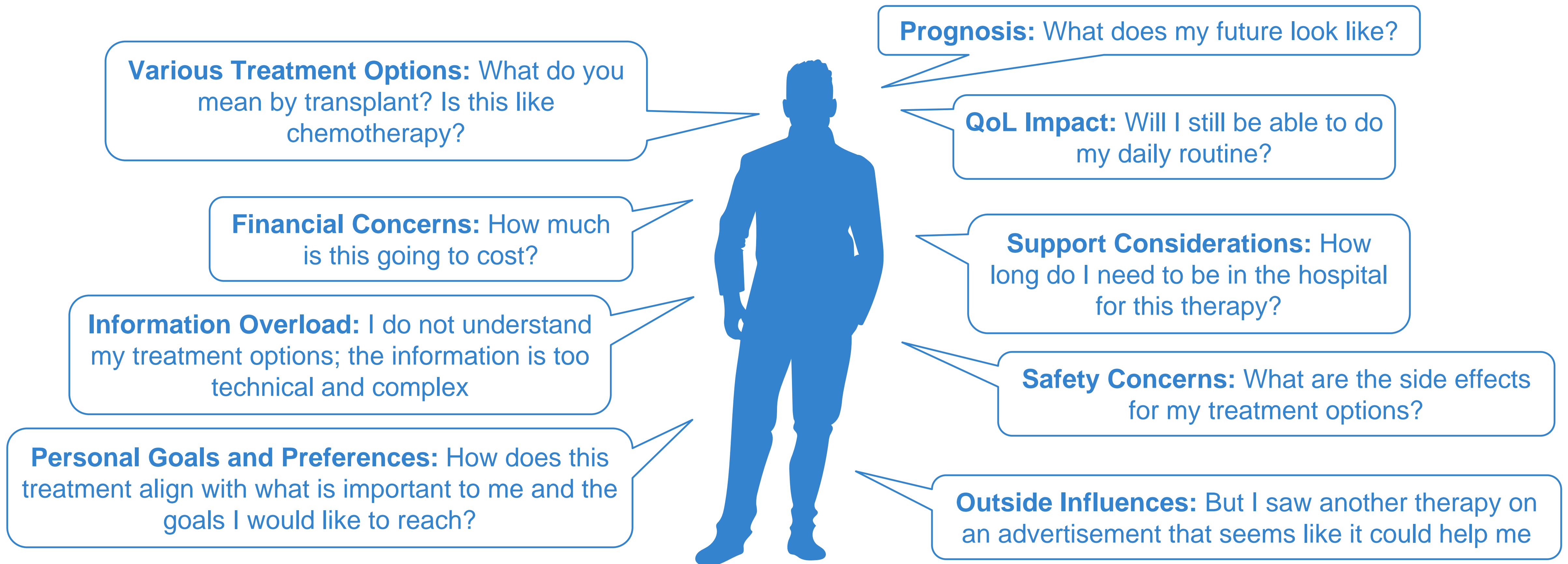
Guidance to Foster Shared Patient Decision Making

- SHARE principles are one way to support patient decision making



Agency for Healthcare Research and Quality. Accessed July 28, 2023. https://www.ahrq.gov/sites/default/files/publications/files/share-approach_factsheet.pdf.

Multiple, Complex Factors Impact the Patient's Decision Making in Oncology



QoL, quality of life.
Glatzer M, et al. *Oncology*. 2020;98(6):370-378.

Chapter 1: Key Takeaways



- Patient decision making occurs when an HCP and patient work together to align on a healthcare decision that is best for the patient¹⁻³
- SHARE (Seek, Help, Assess, Reach, and Evaluate) principles can be used to ensure HCPs engage with patients throughout the decision making journey³
- There is a complex milieu of factors that impact patient decision making in oncology⁴

HCP, healthcare provider.

1. Katz SJ, et al. *J Oncol Pract.* 2014;10(3):206-208. 2. Brown R, et al. *J Clin Oncol.* 2012;30(8):857-862. 3. Agency for Healthcare Research and Quality. Accessed July 28, 2023. https://www.ahrq.gov/sites/default/files/publications/files/share-approach_factsheet.pdf. 4. Glatzer M, et al. *Oncology.* 2020;98(6):370-378.



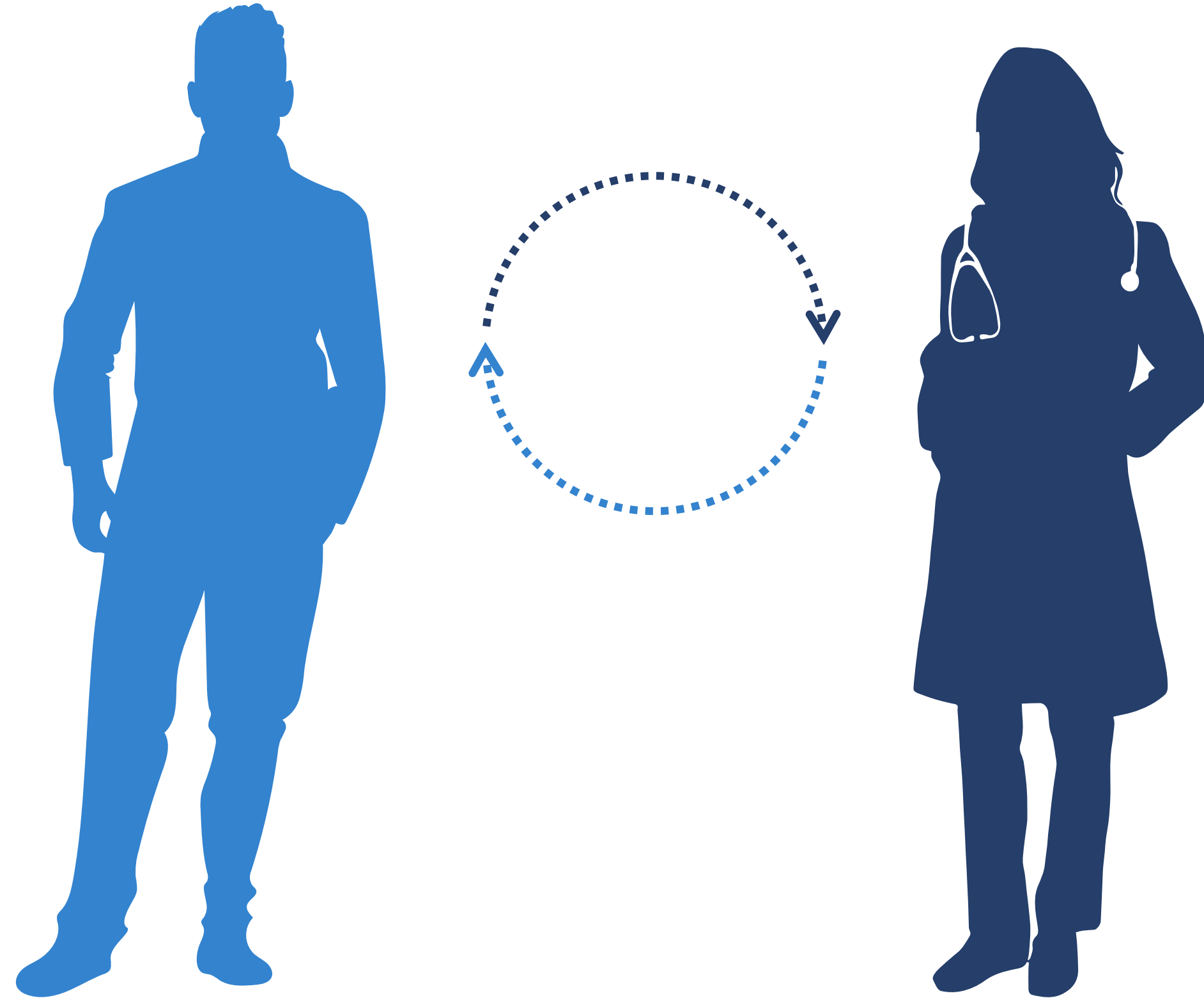
CHAPTER 2: Why Is Patient Involvement in Decision Making Important in Hematologic Malignancies?



Potential Mutual Benefits of Shared Patient Decision Making

Potential Benefits for Patients

- Increased confidence in the healthcare team and patient satisfaction¹⁻³
- Improved adherence to treatment plan^{2,4}
- Patient feels empowered taking ownership of their care^{1,3}



Potential Benefits for HCPs

- Increased patient satisfaction¹⁻³
- Builds more trust with patient^{1,2}
- Improved adherence to treatment plan^{2,4}
- Personal satisfaction and confidence boost³

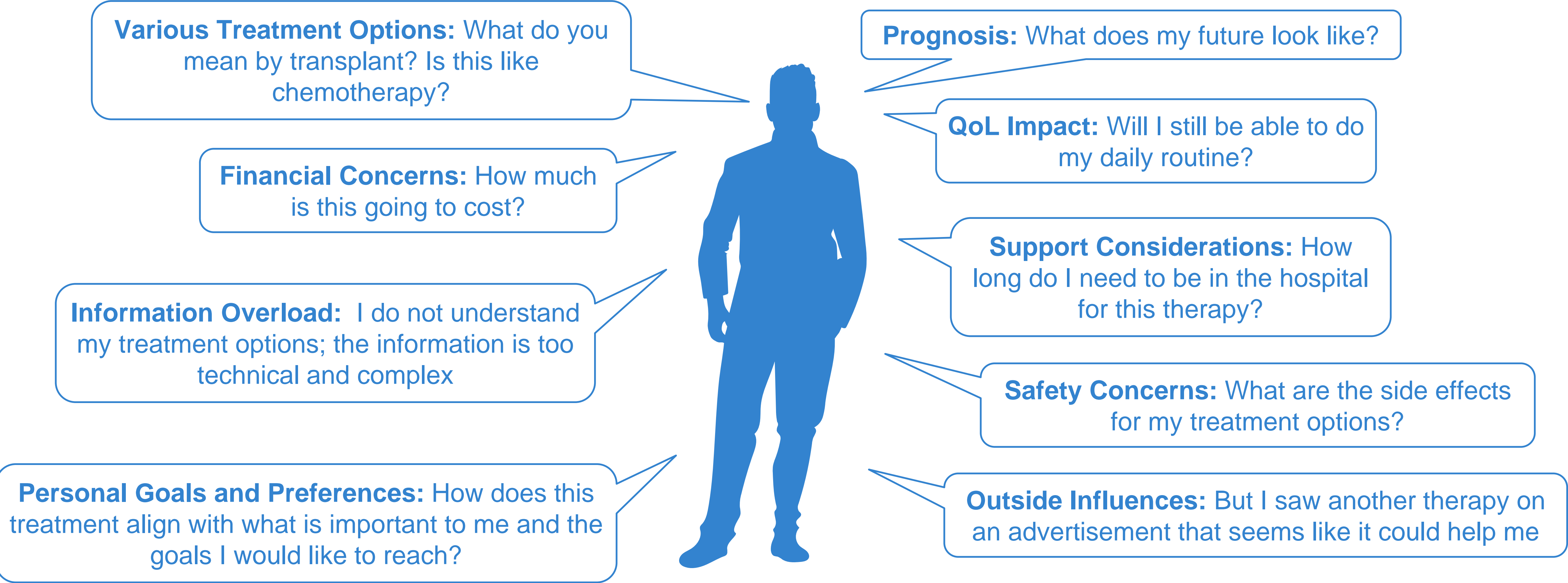
Shared patient decision making may result in improved overall quality of care delivered, benefitting both patients and HCPs^{1,2}

Note: Referenced studies are on patients with solid tumor and hematologic malignancies.

1. Brown R, et al. *J Clin Oncol*. 2012;30(8):857-862. 2. Wunderlich T et al. *Patient Educ Couns*. 2010;80(3): 358–363. 3. Katz SJ, et al. *J Oncol Pract*. 2014;10(3):206-208. 4. Hall AE, et al. *Crit Rev Oncol Hematol*. 2016;97:247-462.



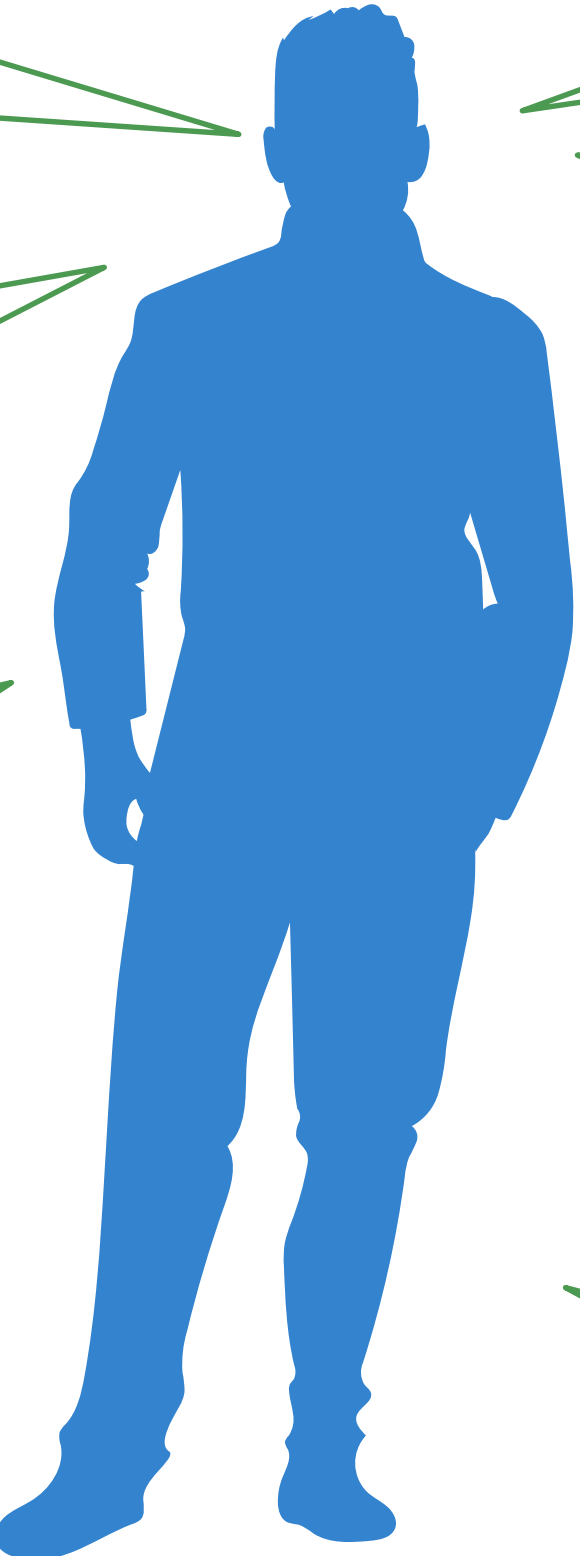
Benefits of Shared Patient Decision Making



Glatzer M, et al. *Oncology*. 2020;98(6):370-378.



Benefits of Shared Patient Decision Making



Various Treatment Options: Discussing the various treatment options helps me adhere to the plan and feel empowered about my health

Financial Concerns: Navigating insurance coverage is tricky, but my HCP's team is helping me every step of the way

Information Overload: The education provided by my HCP helped me digest complex guidelines; now I can make the decision that is best for me

Personal Goals and Preferences: I know that my HCP is treating me as an individual, not as a data point; this builds my trust with the healthcare team

Prognosis: Honest, candid conversations help me to plan for the future

QoL Impact: Discussing how my personal interests and hobbies will be impacted makes me feel more in control of my care

Support Considerations: Knowing how much support I will need during my treatments helps me adhere to my treatment plan

Safety Concerns: Knowing what to expect helps me make healthcare decisions

Outside Influences: There is a lot of information out there, but I know I can trust my healthcare team

Glatzer M, et al. *Oncology*. 2020;98(6):370-378.



Chapter 2: Key Takeaways

- Both patients and HCPs may benefit from shared patient decision making¹⁻³
- Shared patient decision making can benefit patients with hematologic malignancies in a variety of ways¹⁻³

1. Brown R, et al. *J Clin Oncol*. 2012;30(8):857-862. 2. Wunderlich T, et al. *Patient Educ Couns*. 2010;80(3): 358–363. 3. Katz SJ, et al. *J Oncol Pract*. 2014;10(3):206-208.

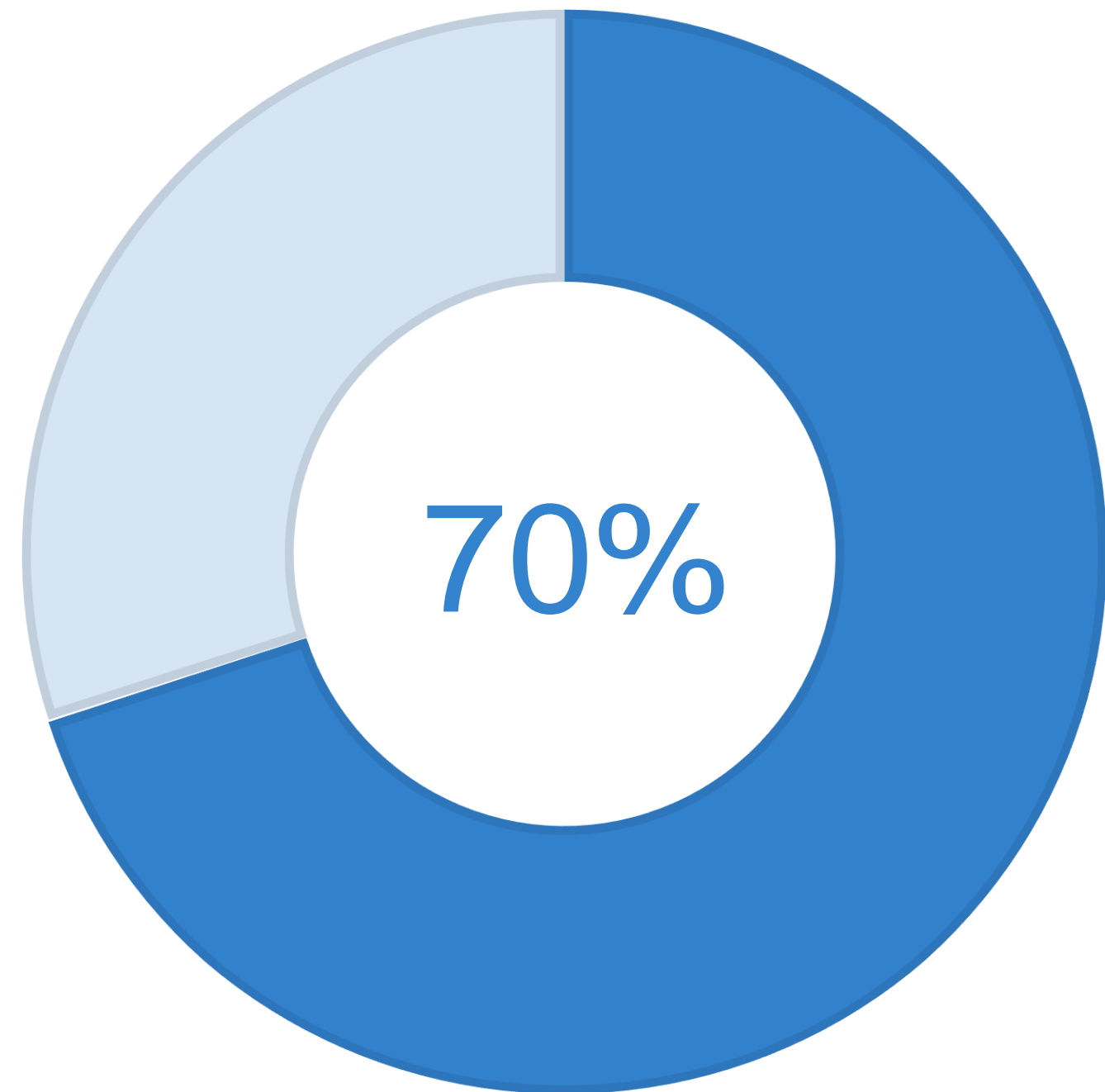


CHAPTER 3: Barriers to Patient Decision Making in Hematologic Malignancies

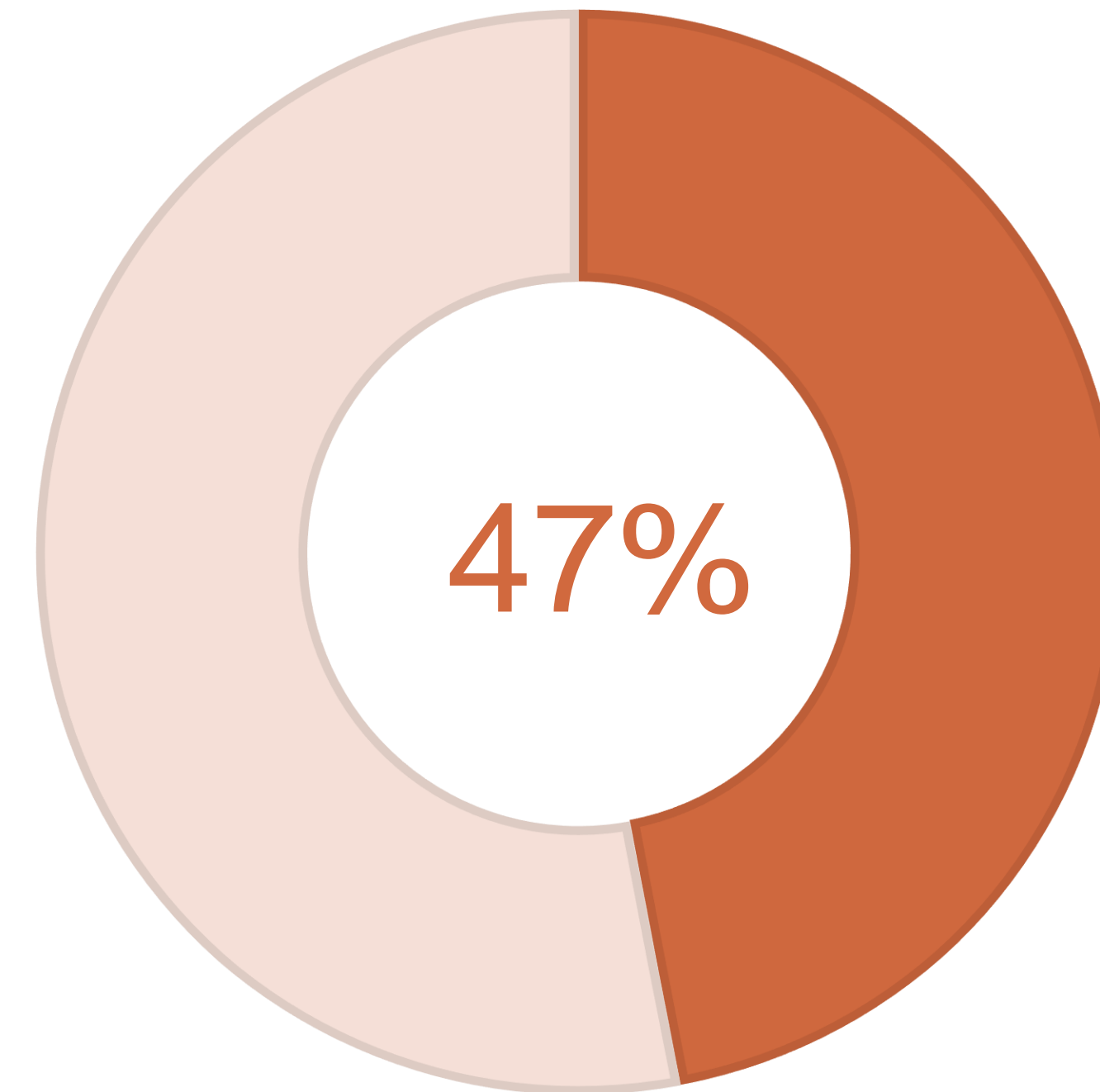
Despite Strong Patient Interest, Shared Patient Decision Making Occurs Insufficiently in Oncology



Patients Who Preferred Shared Decision Making
N=363



Patient-Reported Use of Shared Decision Making^a
N=363

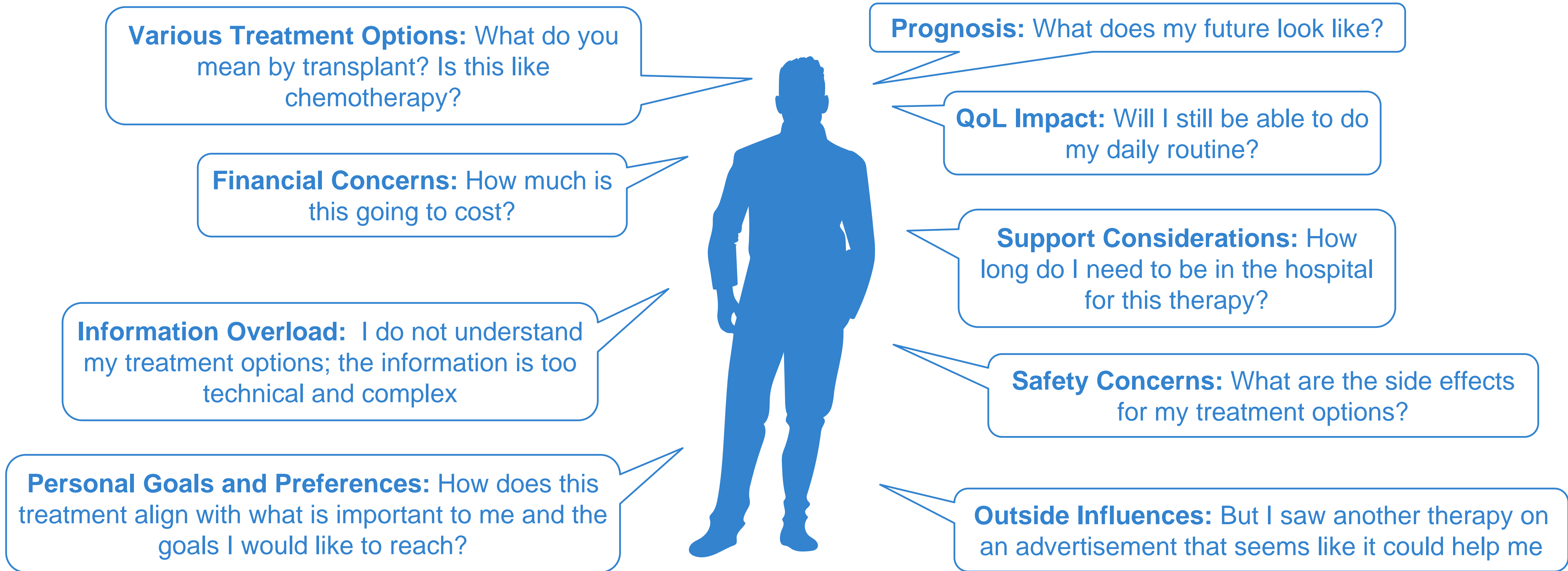


^aOnly one of the decision making reports from patients met all criteria for true shared decision making

Note: Patient participants were insured, between 50 and 80 years old, due for colorectal cancer screening in southeast Michigan between 2007 and 2009. Participants had a pre-visit telephone survey, audio-recording of their visit with the HCP, and post-visit survey.

Wunderlich T, et al. *Patient Educ Couns.* 2010;80(3):358–363.

Barriers to Shared Patient Decision Making: Patient Perspective



1. Katz SJ, et al. *J Oncol Pract.* 2014;10(3):206-208. 2. Glatzer M, et al. *Oncology.* 2020;98(6):370-378.

Barriers to Shared Patient Decision Making: Patient Perspective

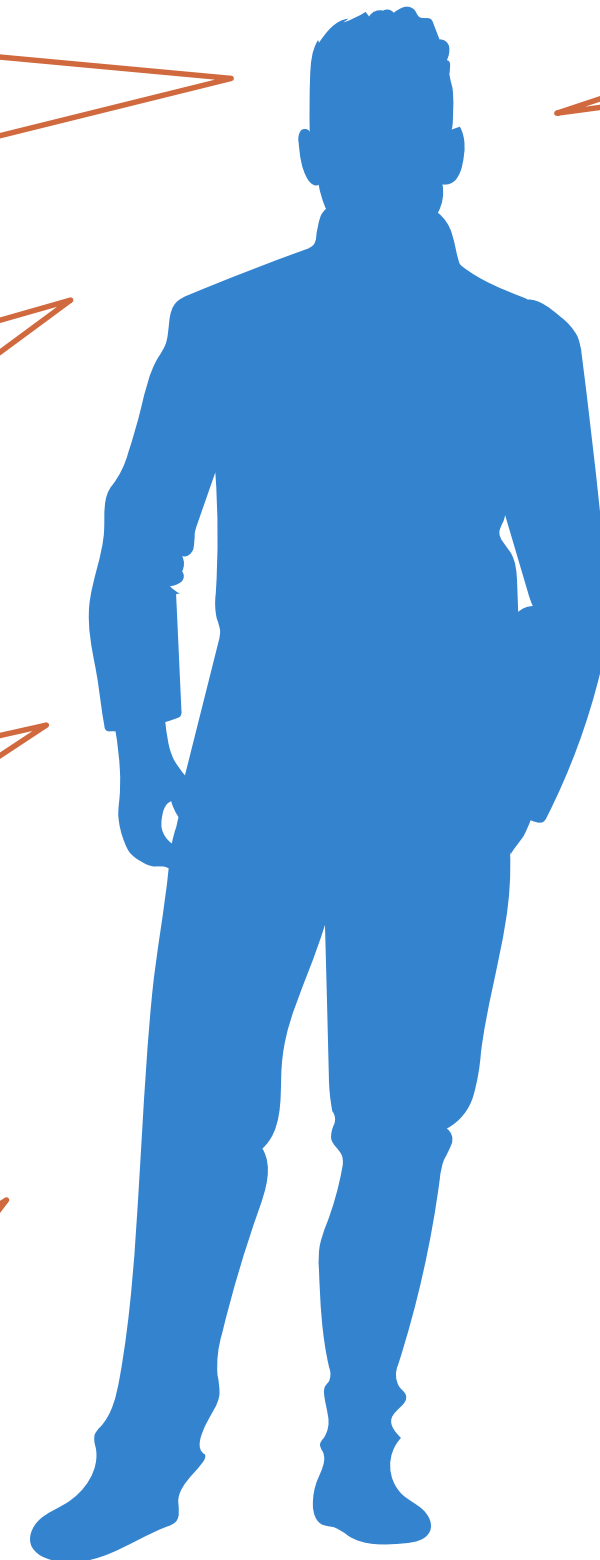


Various Treatment Options: The HCP provided me some general educational material, but this still does not answer my specific questions; the information I am given is not aligning with my need

Financial Concerns: I do not fully understand my treatment plan, so I may stop certain medications due to their expense

Information Overload: My HCP tried to walk me through my treatment options, but I got lost in the jargon - there are so many acronyms and statistics!

Personal Goals and Preferences: If my treatment plan does not align with my goals and preferences, I will just stop the treatment without notifying my HCP since there is probably no other option



Prognosis: I'm like any other patient with cancer; I will be on all sorts of chemotherapy and have poor quality of life

QoL Impact: My HCP does not understand what this means to me and my daily life

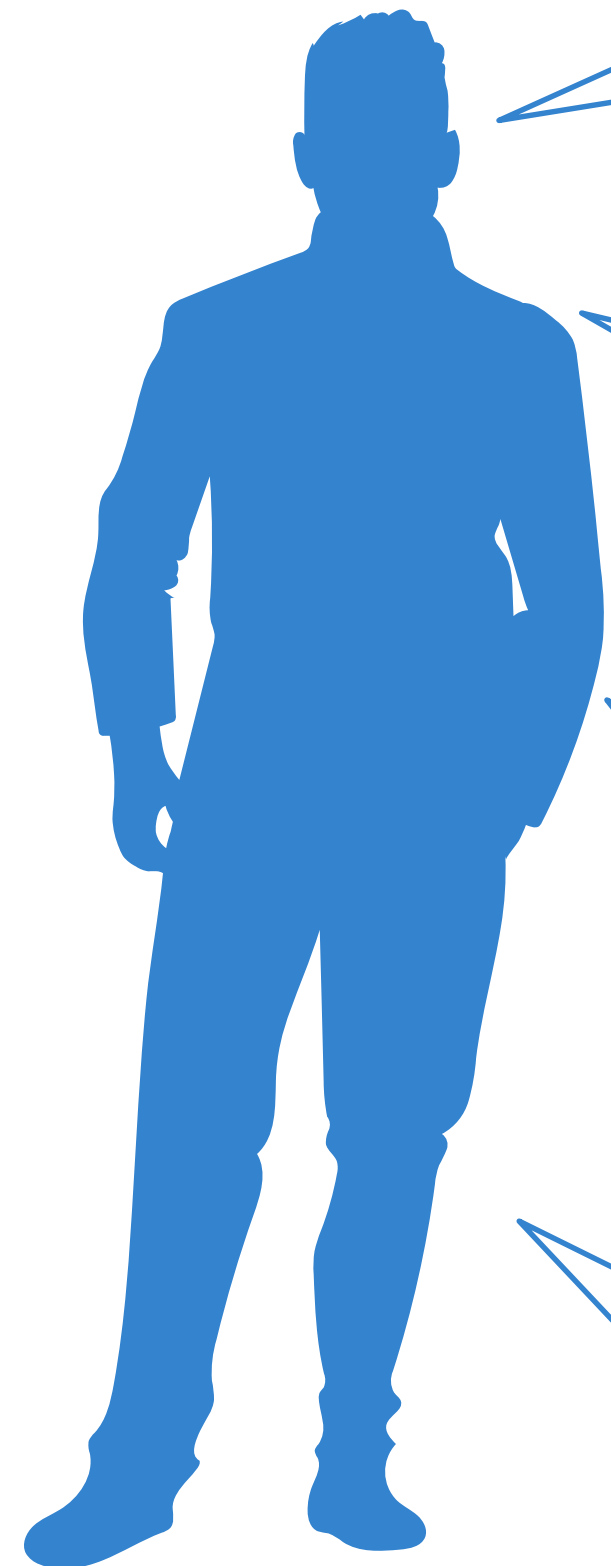
Support Considerations: I need to figure out my support system on my own; my HCP is just here for my physical health

Safety Concerns: All cancer therapies have horrible side effects; I will just have to deal with it or stop the therapy altogether

Outside Influences: My HCP is the expert, but this other treatment on the advertisement makes more sense to me. I looked it up online, but I'm unsure how to discuss this as an option with my HCP

1. Katz SJ, et al. *J Oncol Pract.* 2014;10(3):206-208. 2. Glatzer M, et al. *Oncology.* 2020;98(6):370-378.

Barriers to Shared Patient Decision Making: HCP Perspective



Various Treatment Options: What do you mean by transplant? Is this like chemotherapy?

QoL Impact: Will I still be able to do my daily routine?

Information Overload: I do not understand my treatment options; the information is too technical and complex

Personal Goals and Preferences: How does this treatment align with what is important to me and the goals I would like to reach?

Various Treatment Options: Due to the short appointment, I can give you some educational handouts that I hope will be helpful but may not directly answer all of your questions

QoL Impact: My main priority is to get you in remission. We can adjust therapy if you have an adverse event

Information Overload: I try my best, but the treatment landscape is very complex and understanding key nuances sometimes requires a high level of medical literacy

Personal Goals and Preferences: Out of respect for their privacy, I typically do not ask about patients' personal goals; I tend to prescribe based on objective consensus guidelines

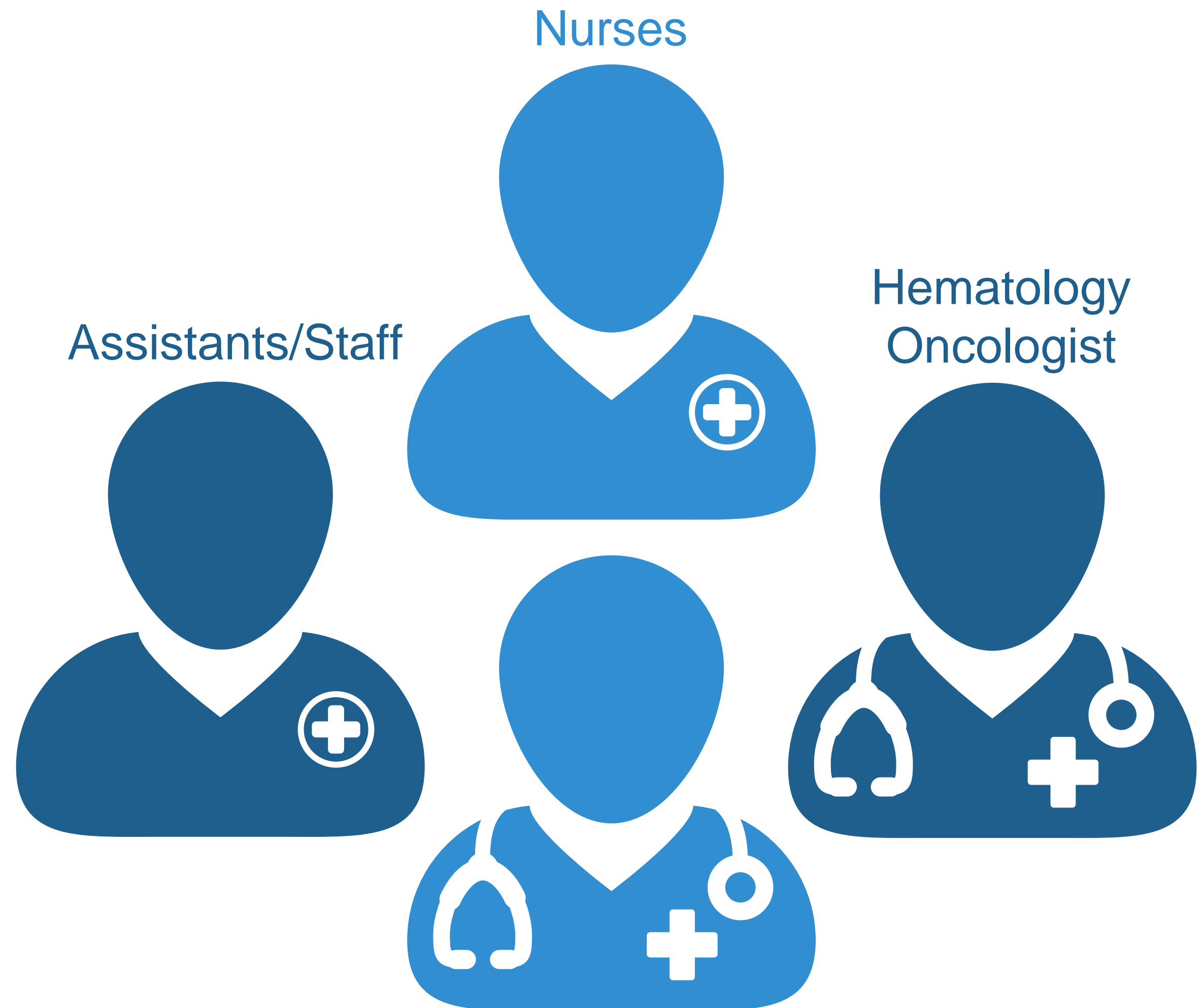


1. Katz SJ, et al. *J Oncol Pract.* 2014;10(3):206-208. 2. Glatzer M, et al. *Oncology.* 2020;98(6):370-378.

Overcoming Shared Decision Making Barriers With Multidisciplinary Teams



- Multidisciplinary teams involve a variety of staff that work together to educate and support the patient to be engaged and empowered in their healthcare¹
- Support from multidisciplinary teams increases the use of shared decision making among hematology/oncology advanced practice professionals²



1. Selby P, et al. *Am Soc Clin Oncol Educ Book*. 2019;39:332-340. 2. Tariman J. *ASH Clinical News*. 2016. Accessed August 14, 2023. <https://ashpublications.org/ashclinicalnews/news/2559/Welcome-to-the-Era-of-Shared-Decision-Making>.



Chapter 3: Key Takeaways

- Although most patients want to participate in decision making, true shared patient decision making occurs insufficiently in oncology¹
- There are numerous barriers to shared decision making for both patients and HCPs, which can lead to inadequate care^{2,3}
- Multidisciplinary teams can help overcome decision making barriers by engaging and empowering patients with hematologic malignancies⁴

1. Wunderlich T, et al. *Patient Educ Couns*. 2010;80(3):358–363. 2. Katz SJ, et al. *J Oncol Pract*. 2014;10(3):206-208. 3. Glatzer M, et al. *Oncology*. 2020;98(6):370-378. 4. Selby P, et al. *Am Soc Clin Oncol Educ Book*. 2019;39:332-340.



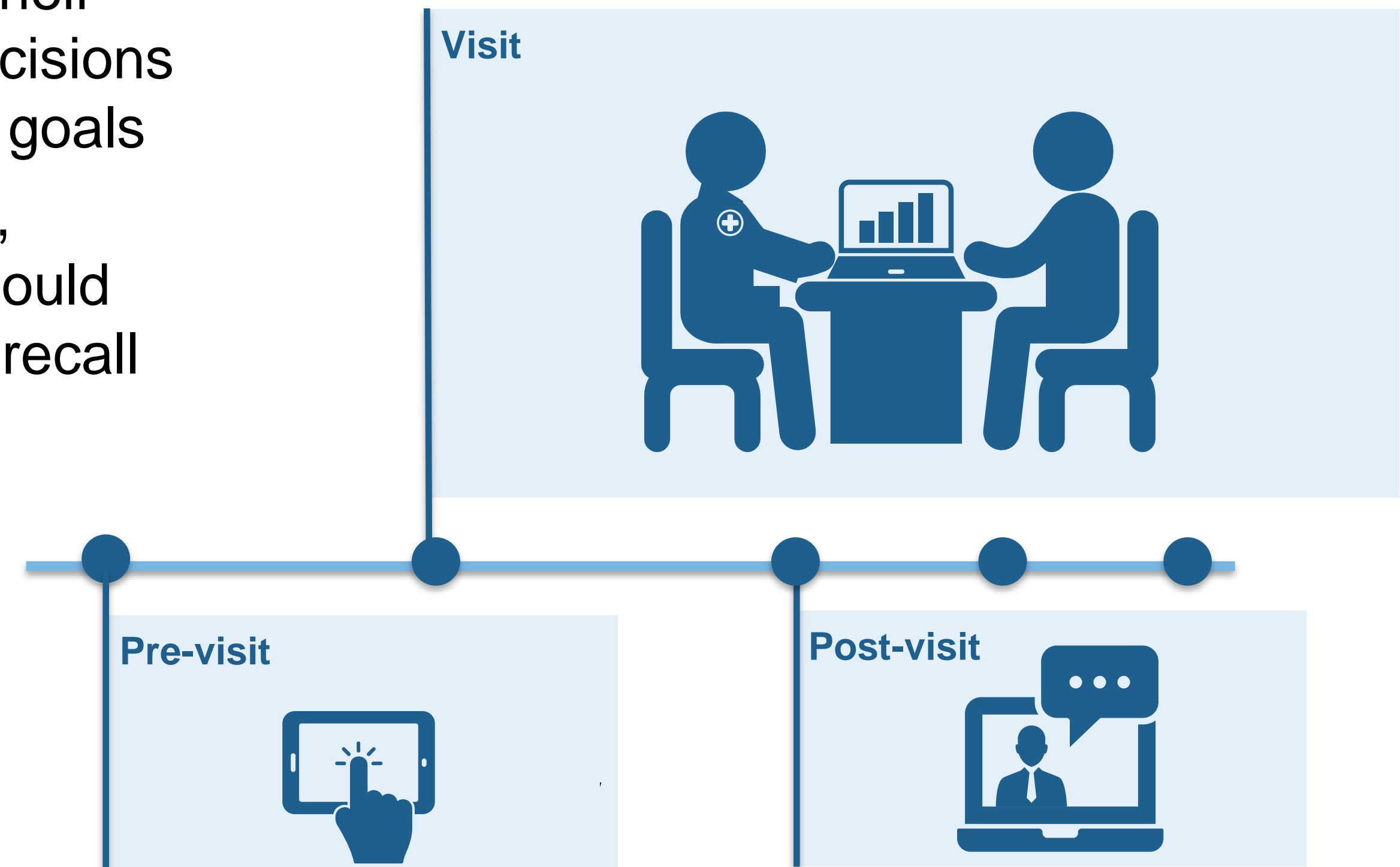
CHAPTER 4: Overcoming Barriers to Patient Decision Making in Hematologic Malignancies Via Patient Decision Aids— A Case Study

Patient Decision Aids Help Guide and Support Patients in Shared Decision Making



- Patient decision aids are tools to help patients and their caregivers make well-informed and personalized decisions consistent with their expectations, preferences, and goals
- The aids can be provided in a variety of formats (eg, pamphlets, interactive websites, and videos), but should include the following to facilitate understanding and recall
 - Able to incorporate into the clinical workflow
 - Comprehensive, critical, current content
 - Personalized to individual preferences and health status
 - Mix of images and text for all literacy needs

Decision Aid Example Case Using a Patient Portal



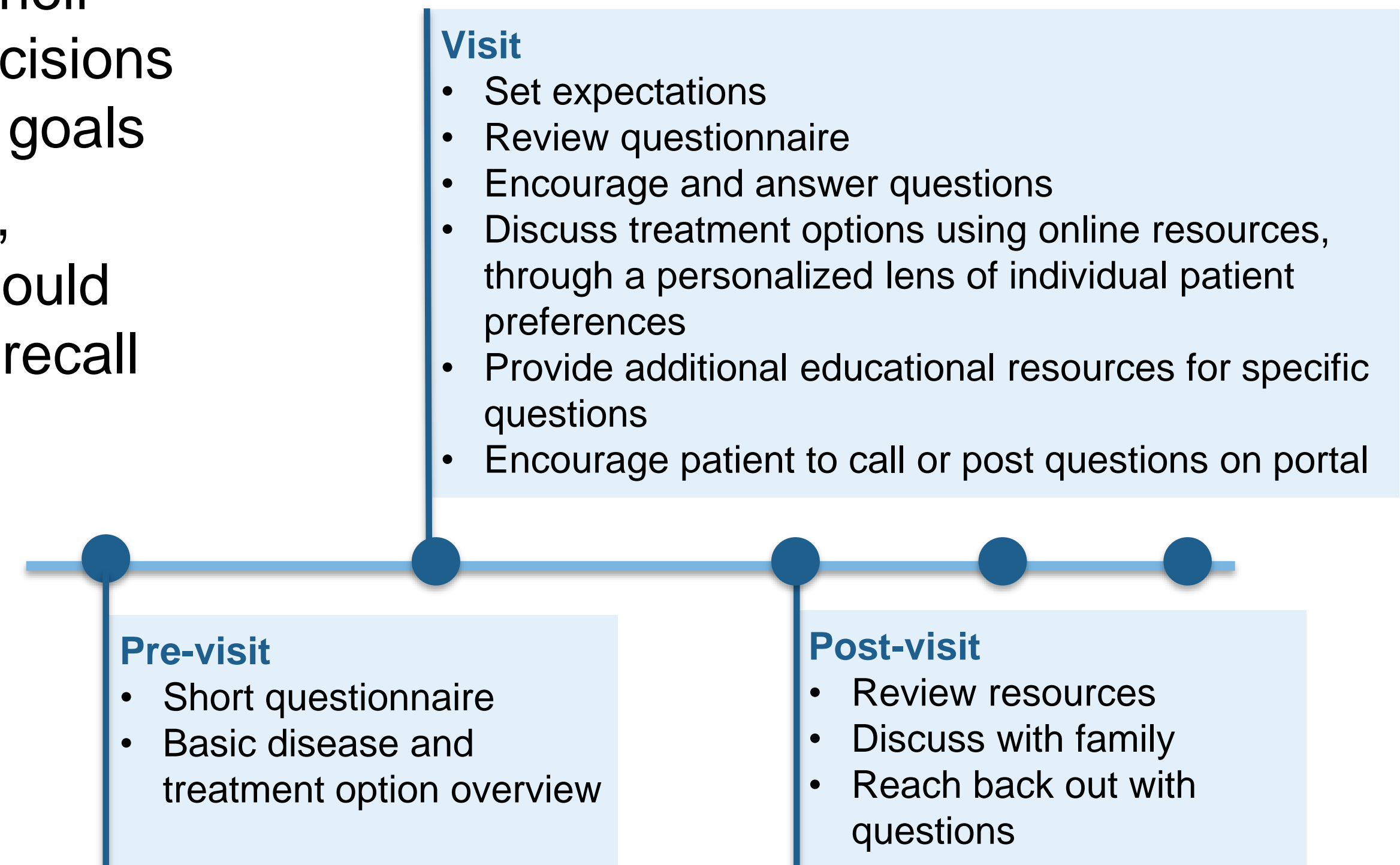
HCPs can support shared decision making among their patients with hematologic malignancies by using decision aids prior to, during, and/or after visits

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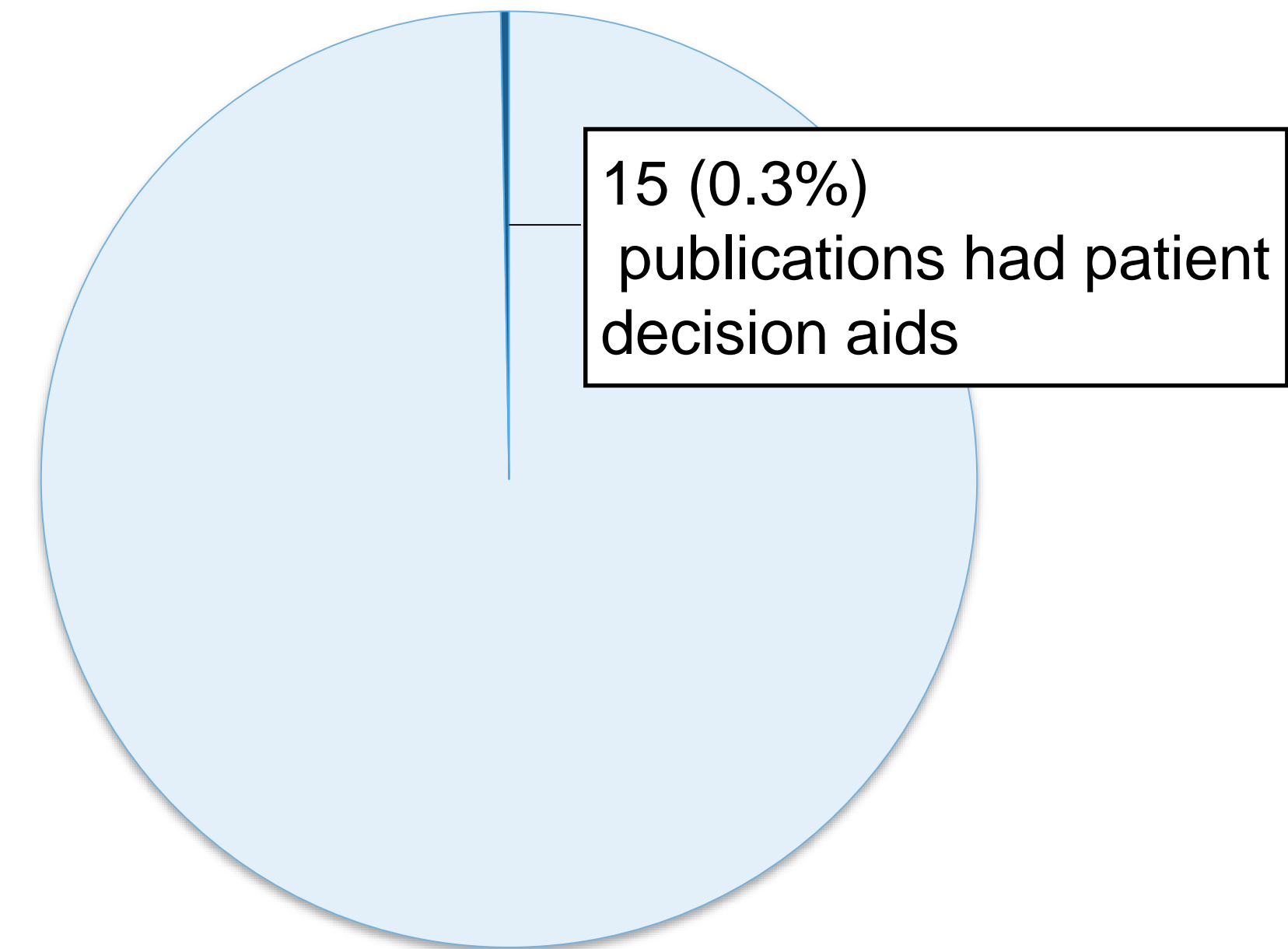
HCPs can support shared decision making among their patients with hematologic malignancies by using decision aids prior to, during, and/or after visits



Patient Decision Aids Increase Patient Satisfaction

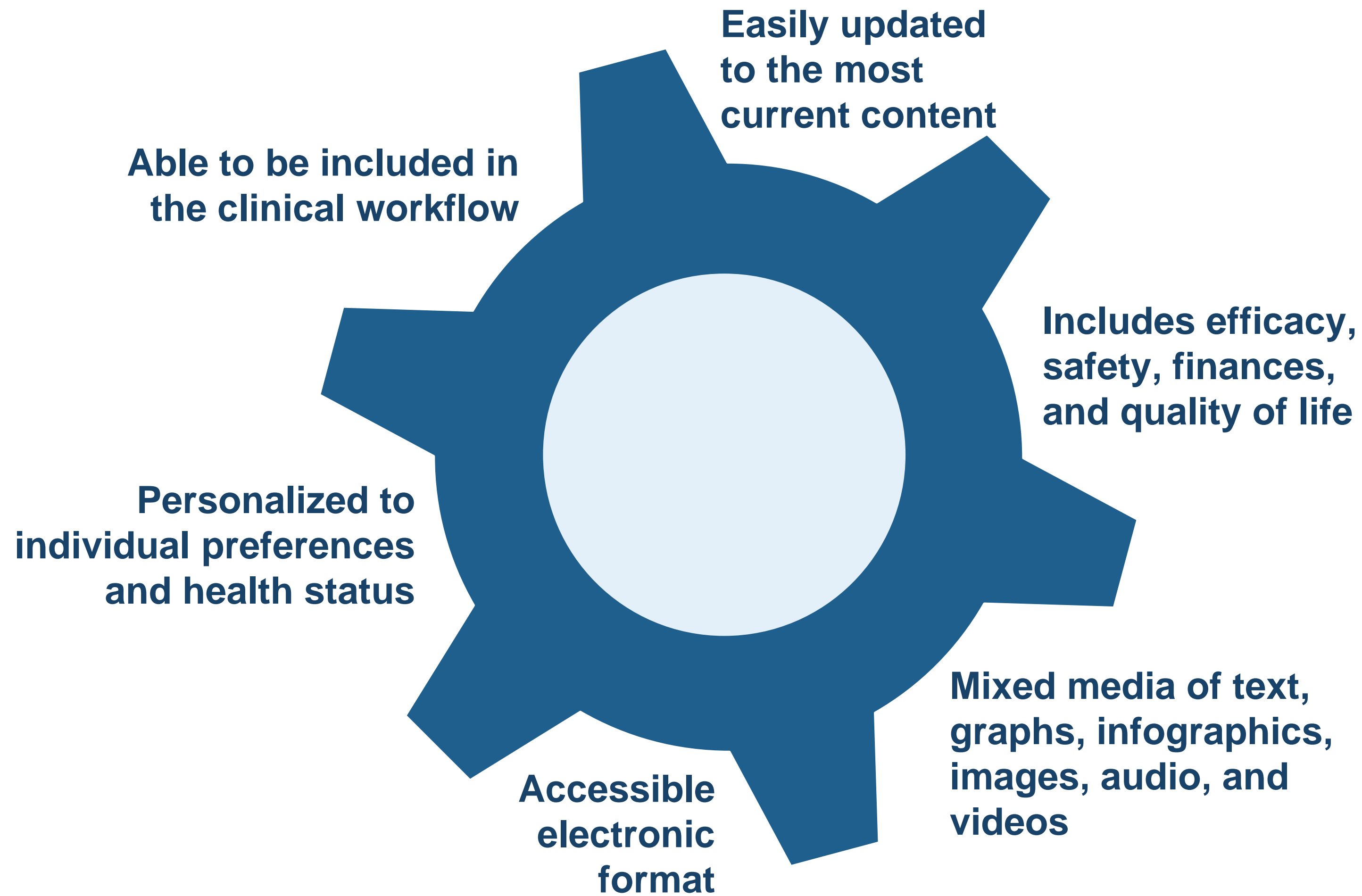
- Using PRISMA criteria in a systematic review, 5281 studies, abstracts, and clinical trial protocols were screened for involvement of patient decision aids for adult patients with hematologic malignancy
- Only 15 publications out of the 5281 screened had patient decision aids (figure)
 - Only 3 out of 15 publications were randomized trials
- Data suggest patient decision aids were associated with increased knowledge and patient satisfaction, as well as decreased decisional conflict and attitudinal barriers

Publications With Patient Decision Aids
in Adult Patients With Hematologic Malignancies
N=5281



Although patient decision aids are not widely studied in hematologic malignancies, the benefits warrant future studies to evaluate the direct impact of decision aids on shared decision making

An Optimal Patient Decision Aid



Zhao J, et al. *Oncologist*. 2023;28(2):105-115.



Chapter 4: Key Takeaways

- HCPs can utilize patient decision aids to help patients and their caregivers make well-informed decisions that align with individual values and goals
- Patient decision aids should have current, individualized content covering efficacy, safety, quality of life, and financial consideration relayed in a clear, mixed-media format



CHAPTER 5: Overcoming Barriers to Patient Decision Making in MCL— A Case Study

Patient Decision Aids May Help Patients Navigate the Complexity of Treatment Options for R/R MCL



- MCL treatment options are complex, particularly in the relapsed/refractory setting

MCL

Diagnosis

First-line therapy is based on patient specific risk factors

First-line Therapy Options

There are over 10 types/combo therapies for first-line treatment

R/R Therapy Options

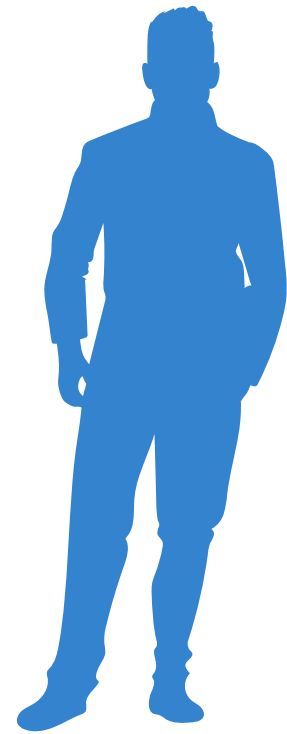
Based on the patient's response to previous line(s) of therapy, there are around 15 types/combo therapies

R/R, relapsed/refractory.
Robak T, et al. *Leuk Lymphoma*. 2019;60(11):2622-2634.

HCP and Patient Perceptions Differ on Key Decision Determinants for Patients With R/R MCL



Patient Interviews Outcomes



- Patients ranked decision determinants as the following:
 1. Efficacy
 2. Safety
 3. Cost
 4. Impact of daily life
- Patients want to be involved in decision making
- Online format is preferred
- Patients typically find information online but feel most information on MCL is incorrect and/or outdated

HCP Interviews Outcomes



- HCPs ranked^a decision determinants as the following:
 1. Cost
 2. Efficacy
 3. Impact of daily life
- HCPs believe patients want to be involved in decision making
- Online format is preferred
- Patients are searching for information and need education on current treatment options due to rapidly evolving treatment landscape

HCPs can better involve patients with R/R MCL in decision making by using decision aids that focus on efficacy, safety, cost, and impact of daily life

^aRanked by how HCPs think what their patients would prioritize.
LeBlanc TW, et al. *Blood*. 2015;125(23):5634.



Examples of Decision Making Tools for Patients With MCL

- HCPs can utilize patient-friendly resources for MCL as a decision aid during shared decision making (*examples below*)

Interactive Videos for Disease, Diagnosis, and Treatment Overviews¹



Patient Journey Fact Sheets^{2,3}



MCL Mobile Applications⁴



- Application includes:
- MCL content
 - Track medications and blood work
 - Log symptoms and side effects

1. Leukemia & Lymphoma Society. Accessed August 14, 2023. <https://www.lls.org/3d-model-library/non-hodgkin-lymphoma-3d-model>. 2. Leukemia & Lymphoma Society. Accessed August 14, 2023. https://www.lls.org/sites/default/files/2023-05/FS4_Mantle_Cell_Facts_0423rev.pdf. 3. Lymphoma Research Foundation. Accessed August 14, 2023. https://lymphoma.org/wp-content/uploads/2023/04/LRF_Mantle_Cell_Lymphoma_RR_Factsheet.pdf. 4. Lymphoma Research Foundation. Accessed August 14, 2023. <https://lymphoma.org/resources/educationresources/mobileapp/>.



Chapter 5: Key Takeaways

- HCPs can provide streamline treatment options for patients with R/R MCL so patients are not overwhelmed by the complexity of options¹
- Input from patients is essential to customize the decision aid tool and the educational materials for their individual needs since their decision determinants may differ from other patients and HCP perspective²
- HCPs can use publicly available tools for MCL geared for patients³⁻⁶

1. Robak T, et al. *Leuk Lymphoma*. 2019;60(11):2622-2634. 2. LeBlanc TW, et al. *Blood*. 2015;125(23):5634. 3. Leukemia & Lymphoma Society. Accessed August 14, 2023. <https://www.lls.org/3d-model-library/non-hodgkin-lymphoma-3d-model>. 4. Leukemia & Lymphoma Society. Accessed August 14, 2023. https://www.lls.org/sites/default/files/2023-05/FS4_Mantle_Cell_Facts_0423rev.pdf. 5. Lymphoma Research Foundation. Accessed August 14, 2023. https://lymphoma.org/wp-content/uploads/2023/04/LRF_Mantle_Cell_Lymphoma_RR_Factsheet.pdf. 6. Lymphoma Research Foundation. Accessed August 14, 2023. <https://lymphoma.org/resources/educationresources/mobileapp/>.



SUMMARY



Summary



- Patient decision making occurs when an HCP and patient work together to align on a healthcare decision that is best for the patient¹
- Both patients and HCPs may benefit from shared patient decision making, which may lead to improved quality of care¹⁻³
- Patients want to be involved in the decision making process, and multidisciplinary teams may provide opportunities for patients to engage^{3,4}
- HCPs can use patient decision aids to help patients make well-informed decisions that align with individual values and goals and reduce decisional conflict⁵
- Given the complex treatment options for patients with hematologic malignancies, shared patient decision making may help better align treatment decisions with patients' values and preferences^{6,7}

1. Katz SJ, et al. *J Oncol Pract.* 2014;10(3):206-208. 2. Brown R, et al. *J Clin Oncol.* 2012;30(8):857-862. 3. Wunderlich T, et al. *Patient Educ Couns.* 2010;80(3):358–363. 4. Selby P, et al. *Am Soc Clin Oncol Educ Book.* 2019;39:332-340. 5. Zhao J, et al. *Oncologist.* 2023;28(2):105-115. 6. Robak T, et al. *Leuk Lymphoma.* 2019;60(11):2622-2634. 7. LeBlanc TW, et al. *Blood.* 2015;125(23):5634.