

Shared Decision Making in Hematologic Malignancies

Learning Objectives

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

Table of Contents

- CHAPTER 1 What Is Shared Decision Making in Hematologic Malignancies?
- CHAPTER 2 Why Is Shared Decision Making Important in Hematologic Malignancies?
- CHAPTER 3 Barriers to Shared Decision Making in Hematologic Malignancies
- CHAPTER 4 Overcoming Barriers to Shared Decision Making in Hematologic Malignancies Via Patient Decision Aids—A Case Study
- CHAPTER 5 Overcoming Barriers to Shared Decision Making in MCL—A Case Study
- CHAPTER 6 Overcoming Barriers to Shared Decision Making in CLL

SUMMARY

All hyperlinks are functional in slide show mode.





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



Shared Decision Making Between HCPs and Patients

- Shared decision making occurs when an HCP and a patient work together to make a health care 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

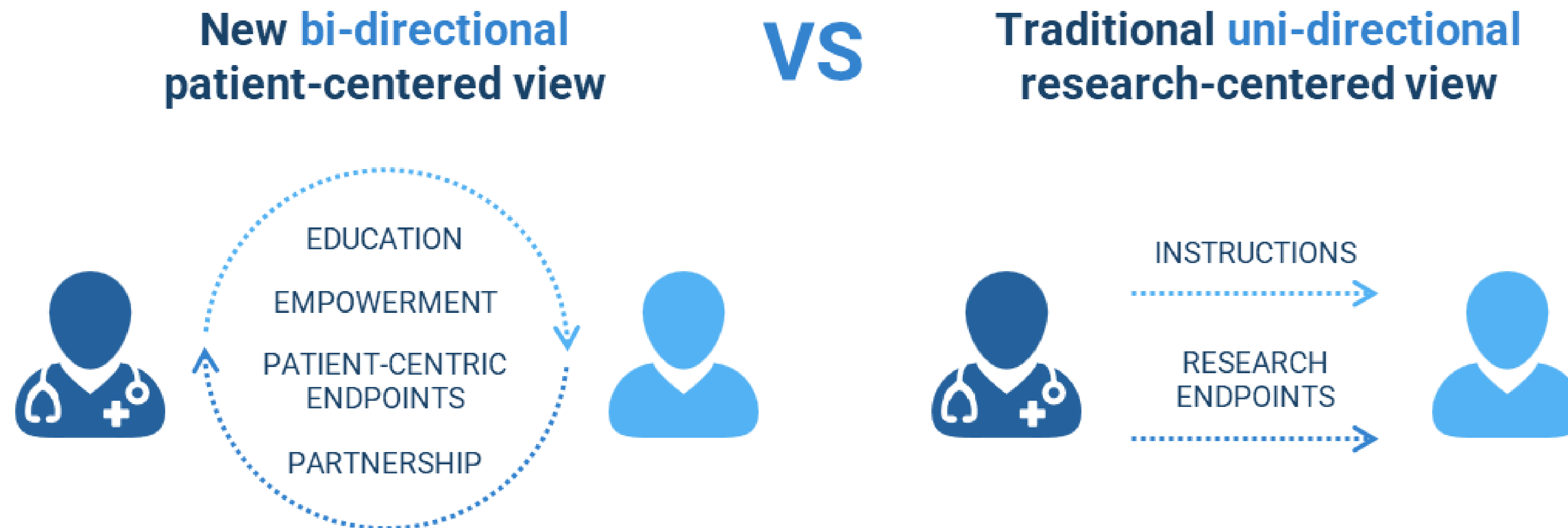


Image adapted from: LUNgevity Transforming Lung Cancer. Accessed August 3, 2023. <https://www.lungevity.org/research/patient-focused-research-center-patient-force/shared-decision-making>.

HCP, health care 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

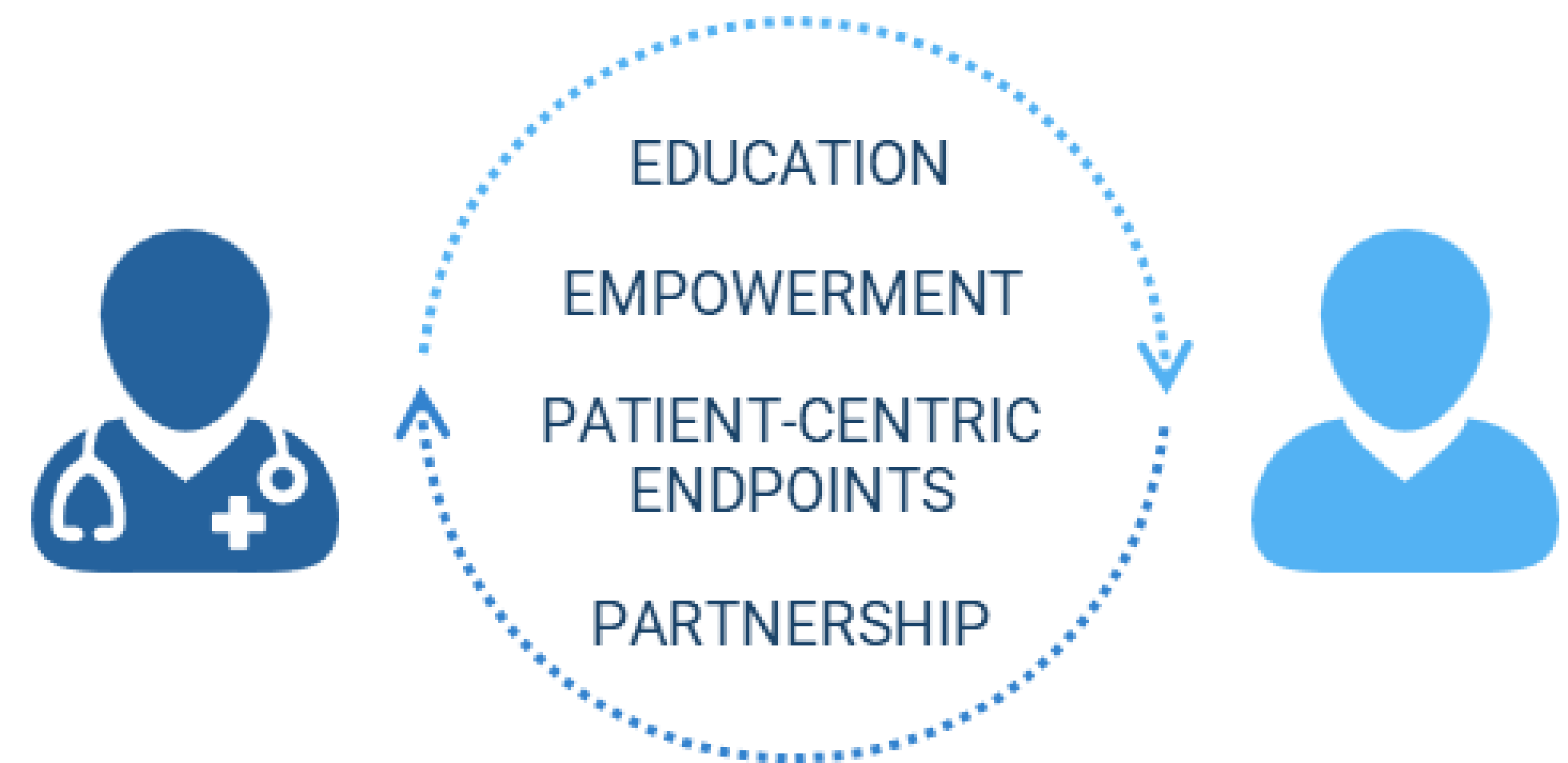


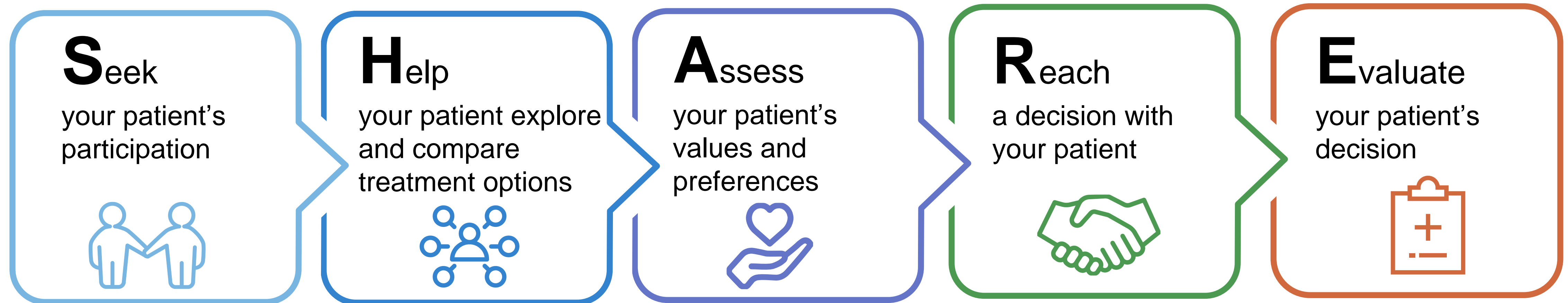
Image adapted from: LUNgevity Transforming Lung Cancer. Accessed August 3, 2023. <https://www.lungevity.org/research/patient-focused-research-center-patient-force/shared-decision-making>.

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

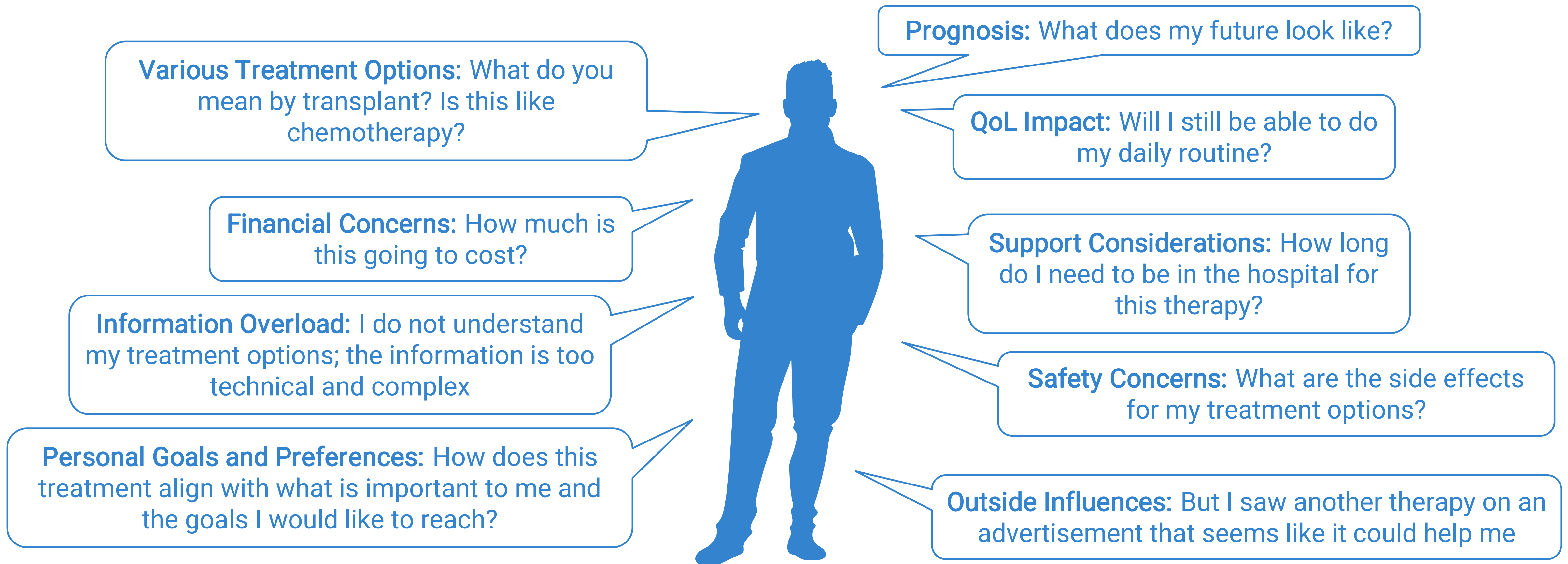


Guidance to Foster Shared Decision Making

- SHARE principles are one way to support shared decision making



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

- Shared 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 shared decision making in oncology⁴

HCP, health care 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.



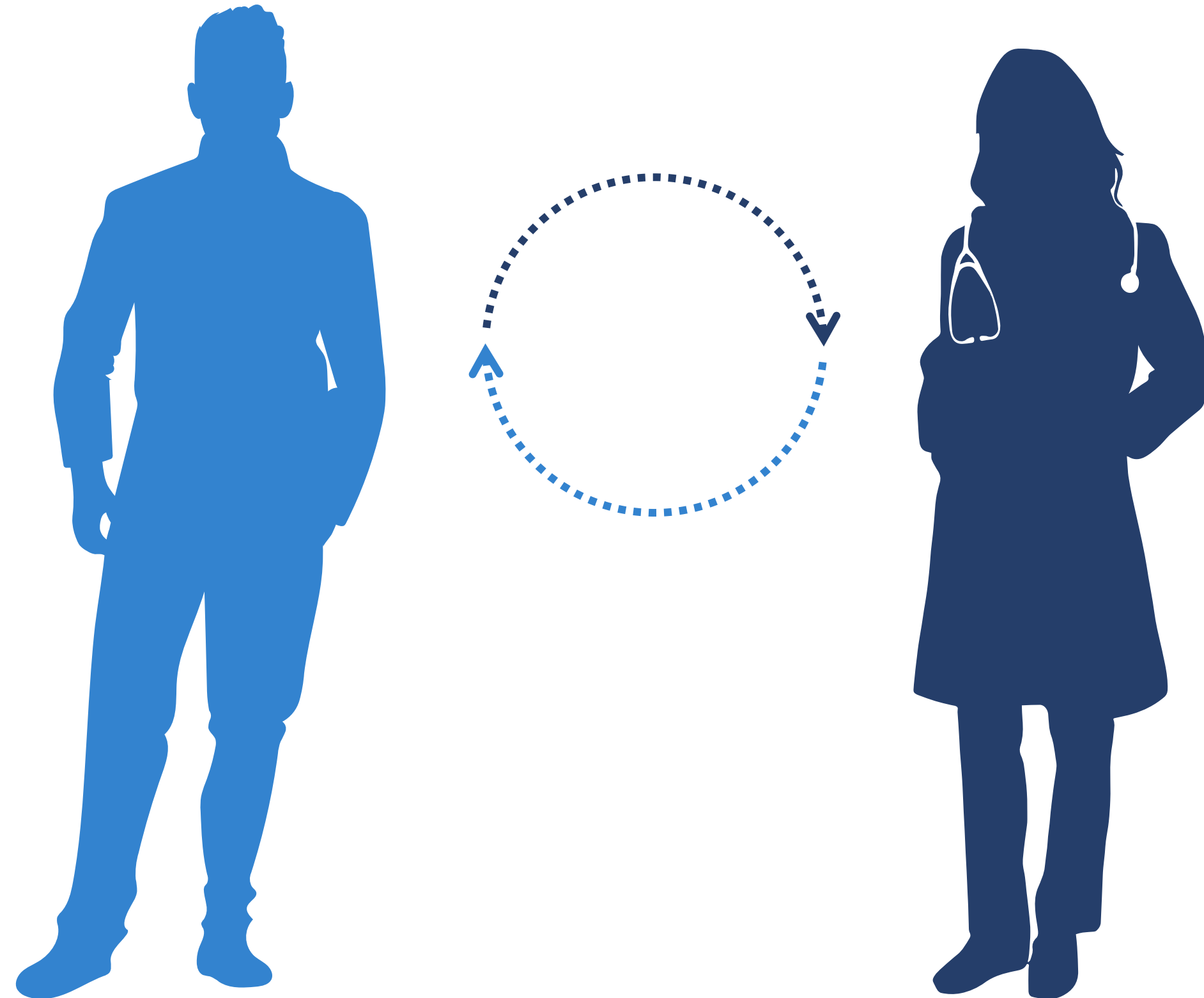
CHAPTER 2: Why Is Patient Involvement in Shared Decision Making Important in Hematologic Malignancies?



Potential Mutual Benefits of Shared 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 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.

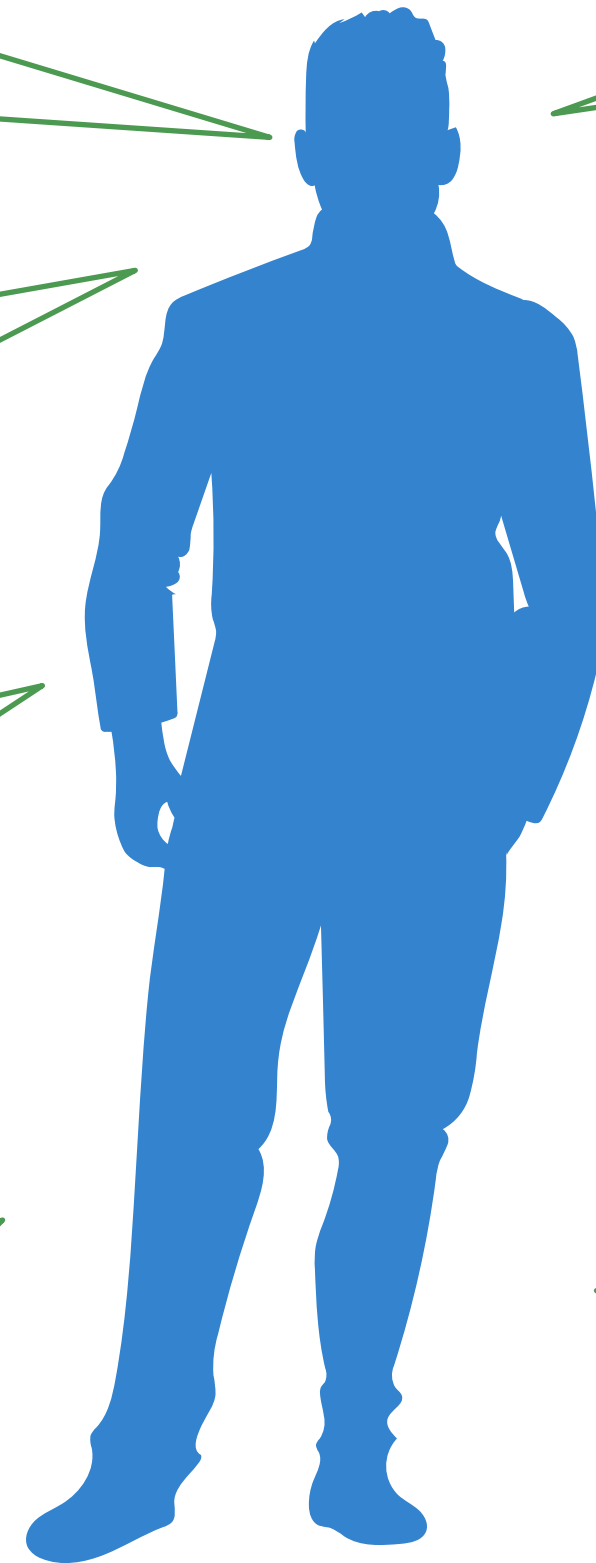
1. Brown R, et al. *J Clin Oncol*. 2012;30(8):857-862. 2. Wunderlich T et al. *Patient Educ Couns*. 2010;80(3): 358–363. 3. Katz SJ, et al. *J Oncol Pract*. 2014;10(3):206-208. 4. Hall AE, et al. *Crit Rev Oncol Hematol*. 2016;97:247-462.

Benefits of Shared Decision Making



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

Benefits of Shared 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

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

Chapter 2: Key Takeaways



- Both patients and HCPs may benefit from shared decision making¹⁻³
- Shared 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.

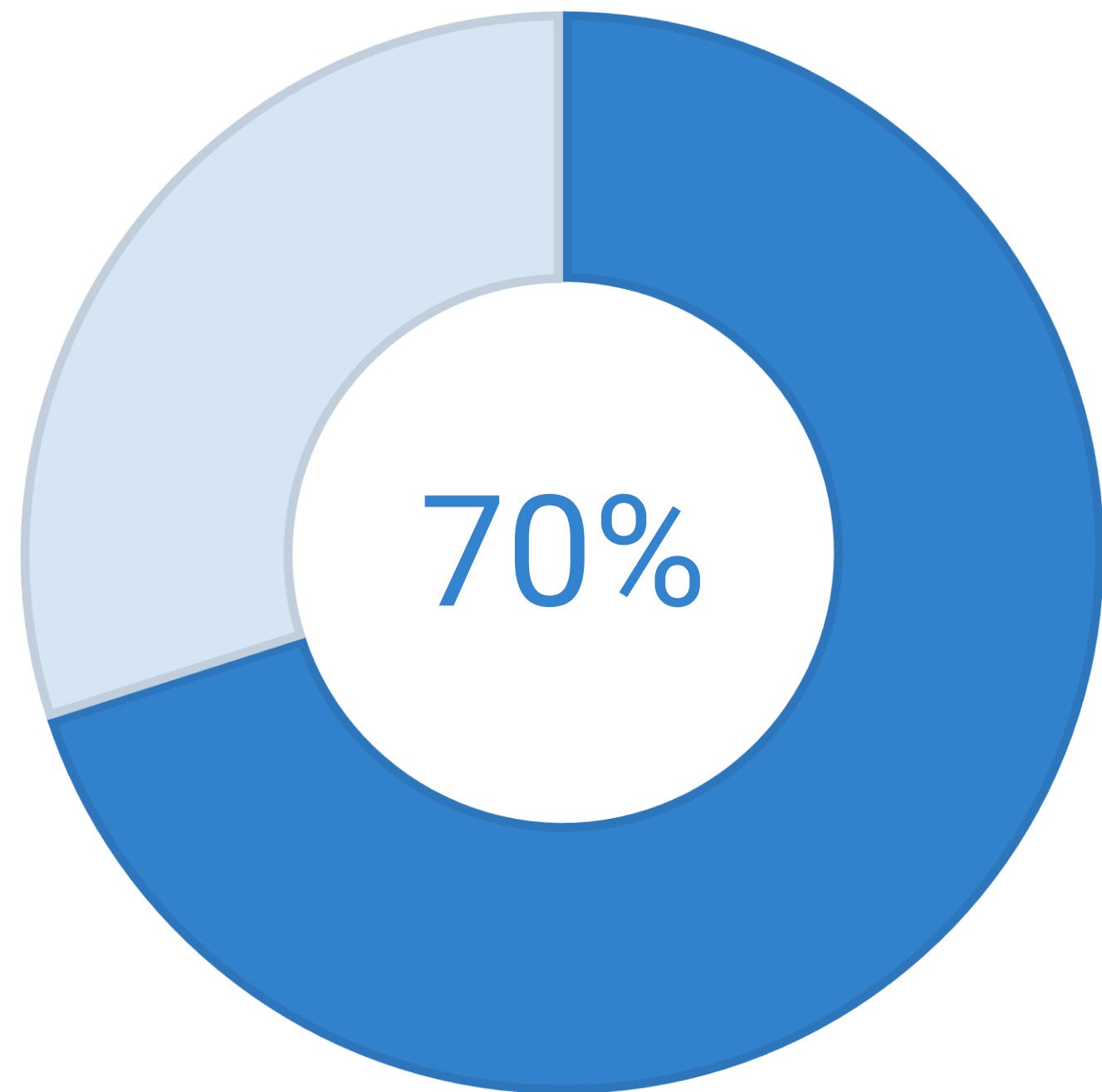


CHAPTER 3: Barriers to Shared Decision Making in Hematologic Malignancies

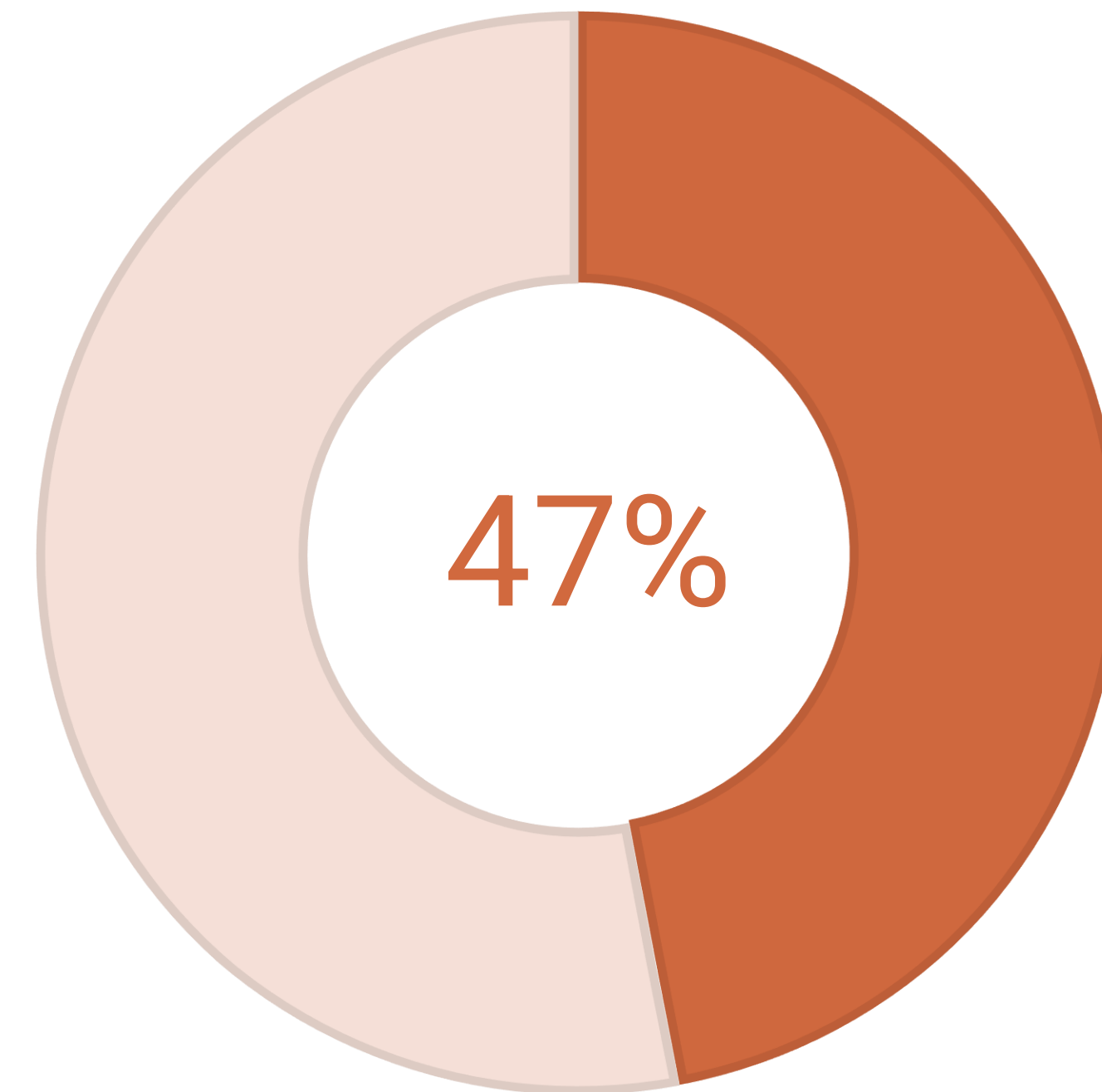
Despite Strong Patient Interest, Shared Decision Making Occurs Insufficiently in Oncology



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 Decision Making: Patient Perspective^{1,2}



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

Financial Concerns: How much is this going to cost?

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?

Prognosis: What does my future look like?

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

Support Considerations: How long do I need to be in the hospital for this therapy?

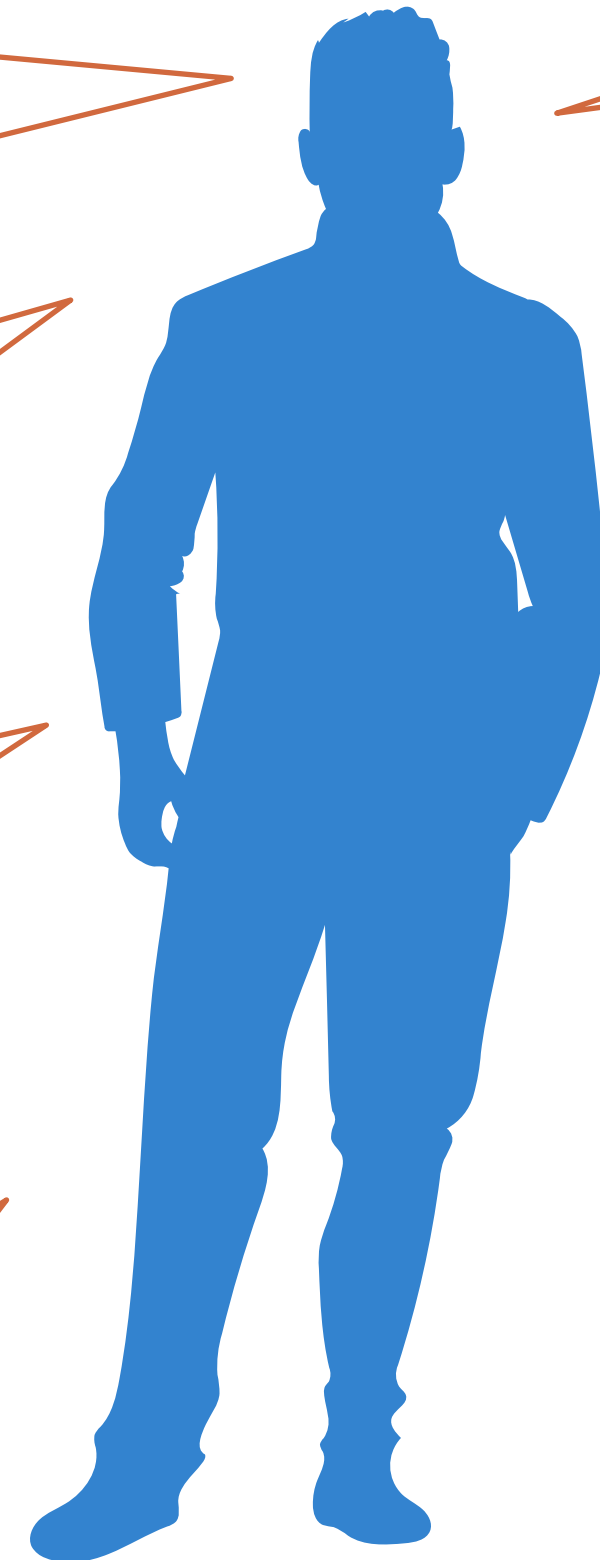
Safety Concerns: What are the side effects for my treatment options?

Outside Influences: But I saw another therapy on an advertisement that seems like it could help me

QoL, quality of life.

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 Decision Making: Patient Perspective^{1,2}



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

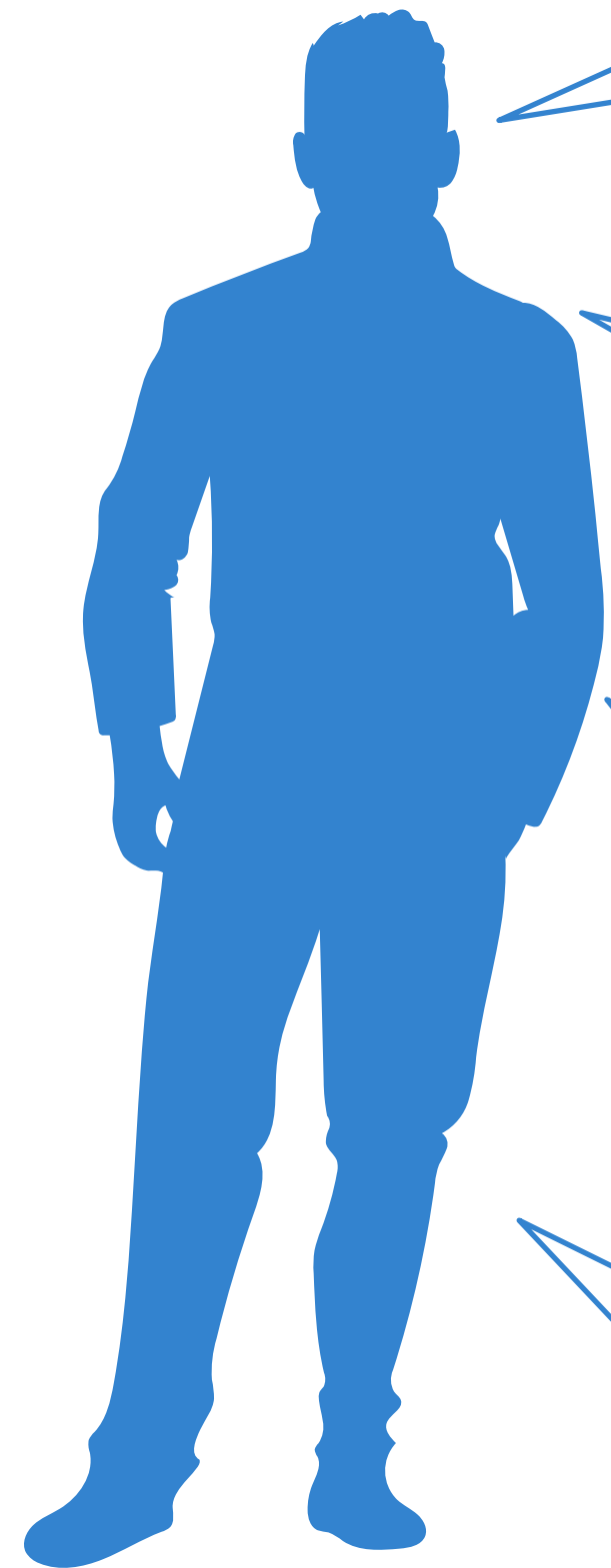
Safety Concerns: All cancer therapies have horrible side effects; I will just have to deal with it or stop the therapy altogether

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

QoL, quality of life.

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 Decision Making: HCP Perspective^{1,2}



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



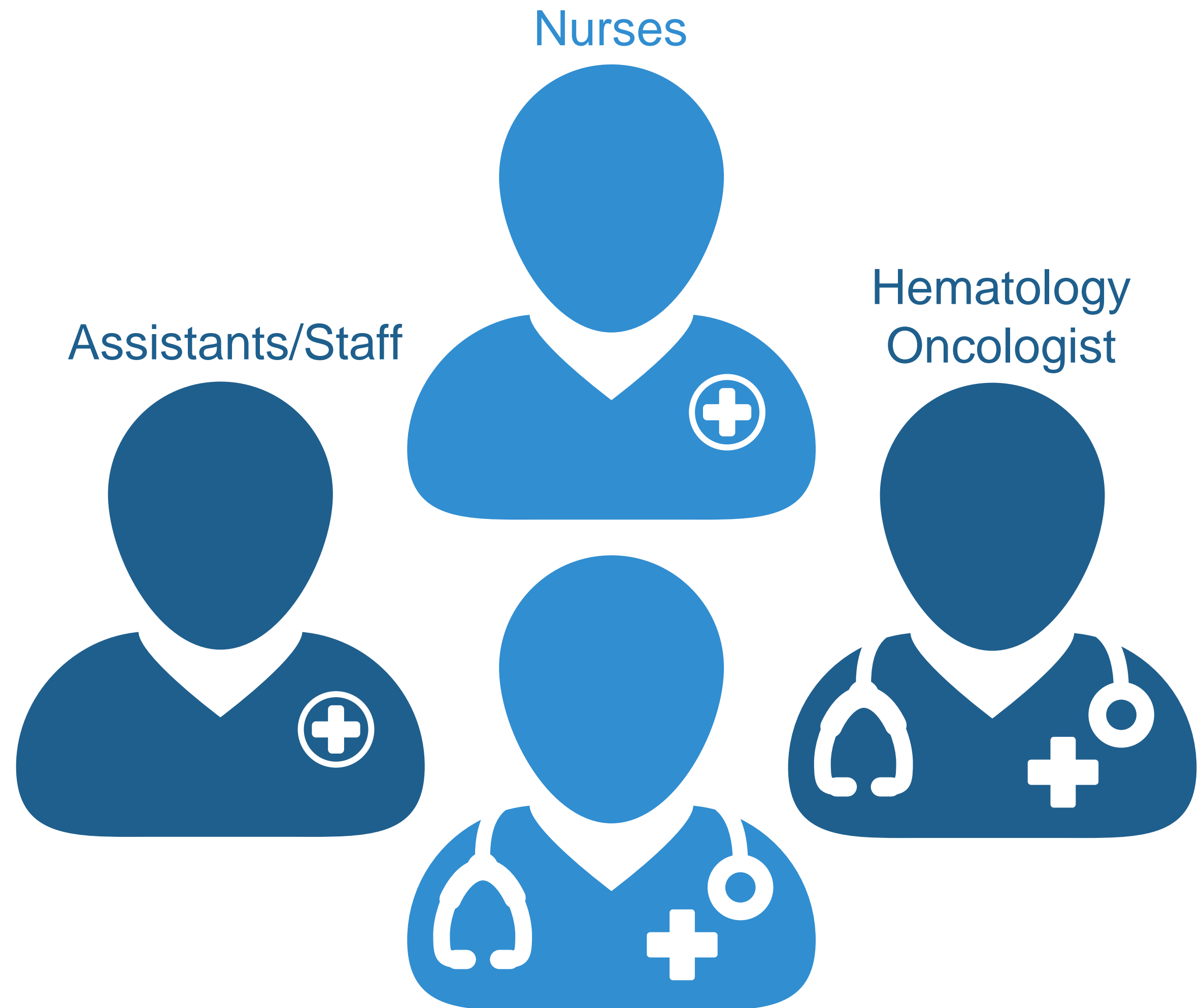
QoL, quality of life.

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



Hematology/Oncology Advanced Practice Professionals

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 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

HCP, health care provider.

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.



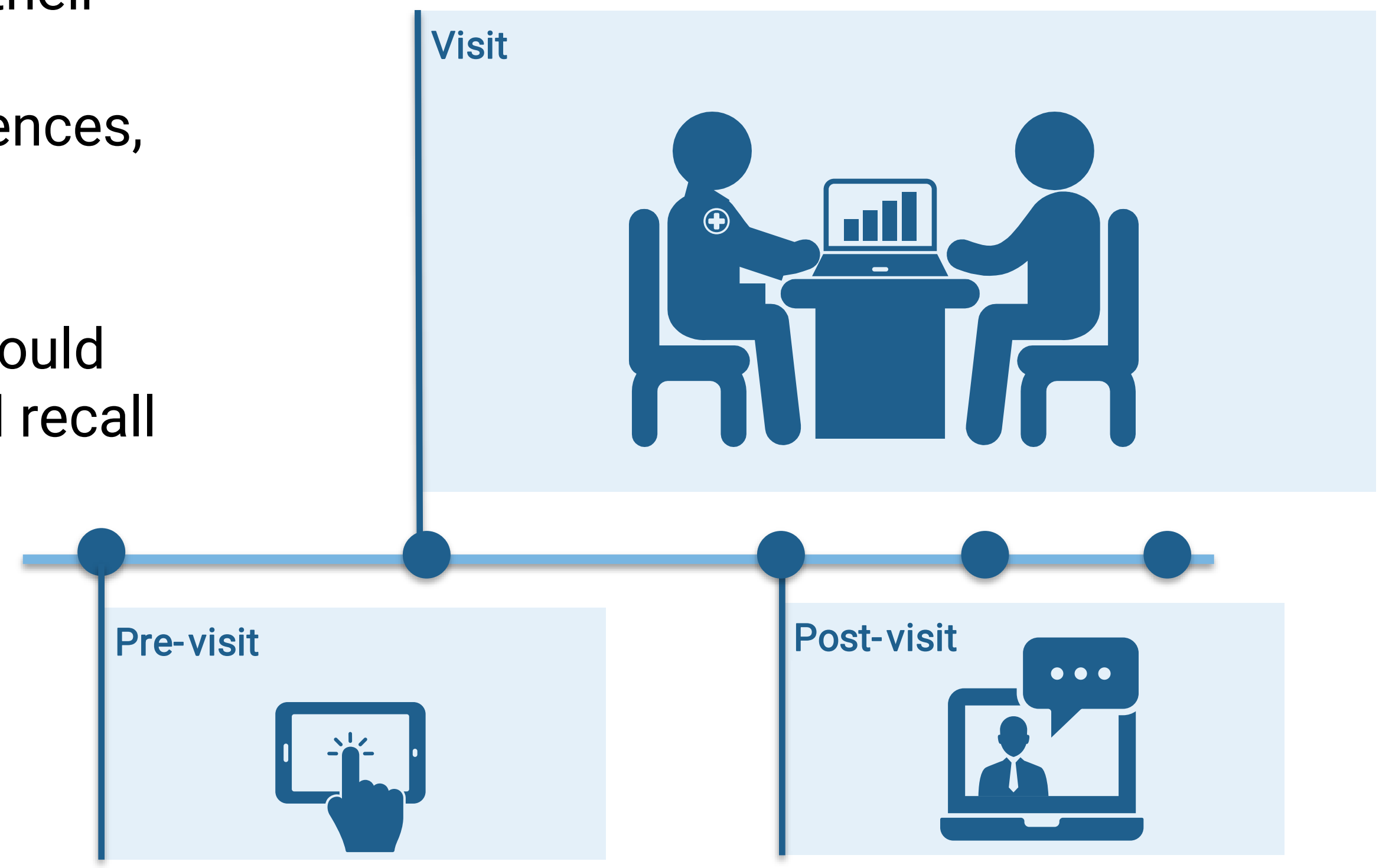
CHAPTER 4: Overcoming Barriers to Shared Decision Making in Hematologic Malignancies Via Patient Decision Aids— A Case Study

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

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

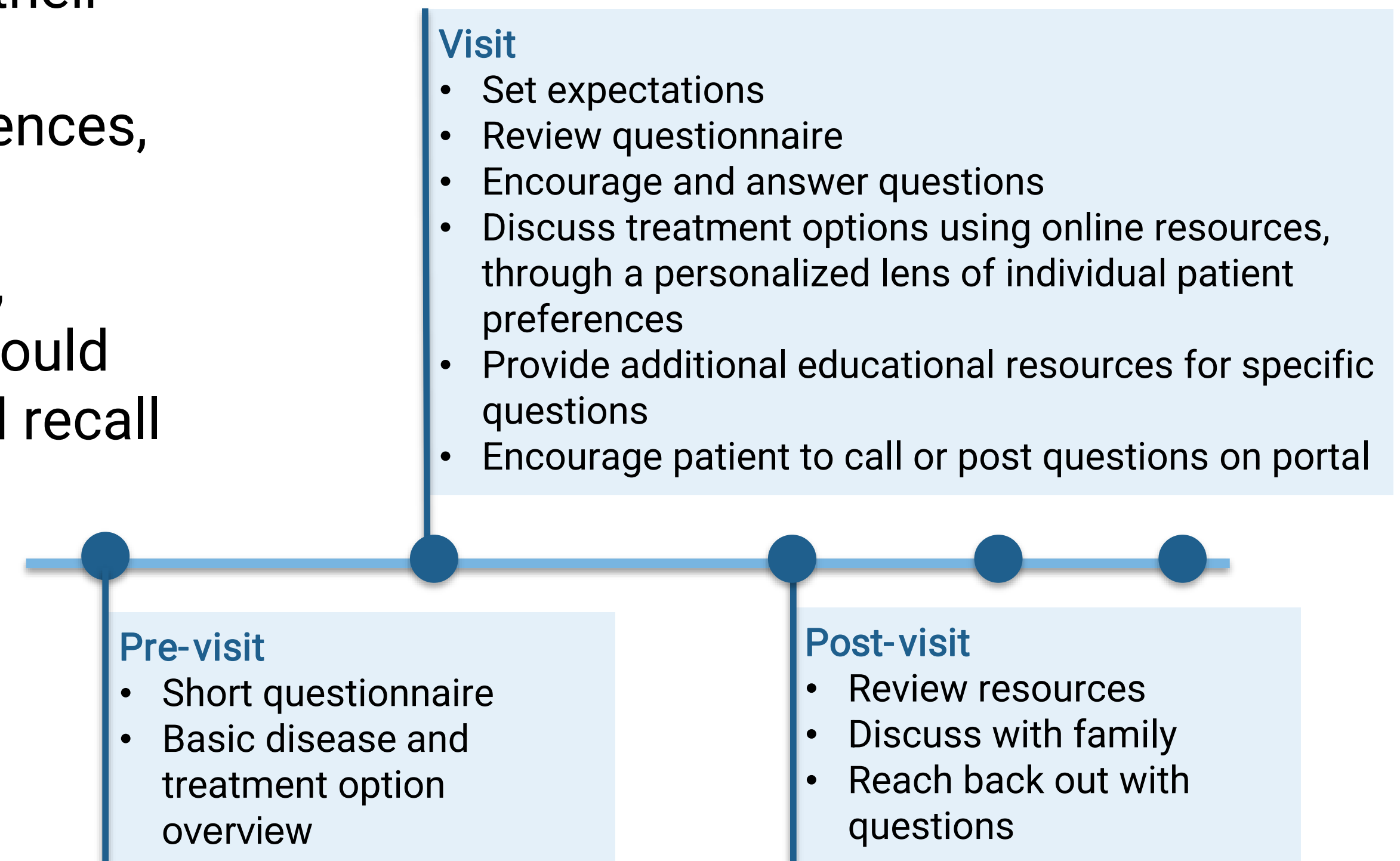


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Decision Aid Example Case Using a Patient Portal



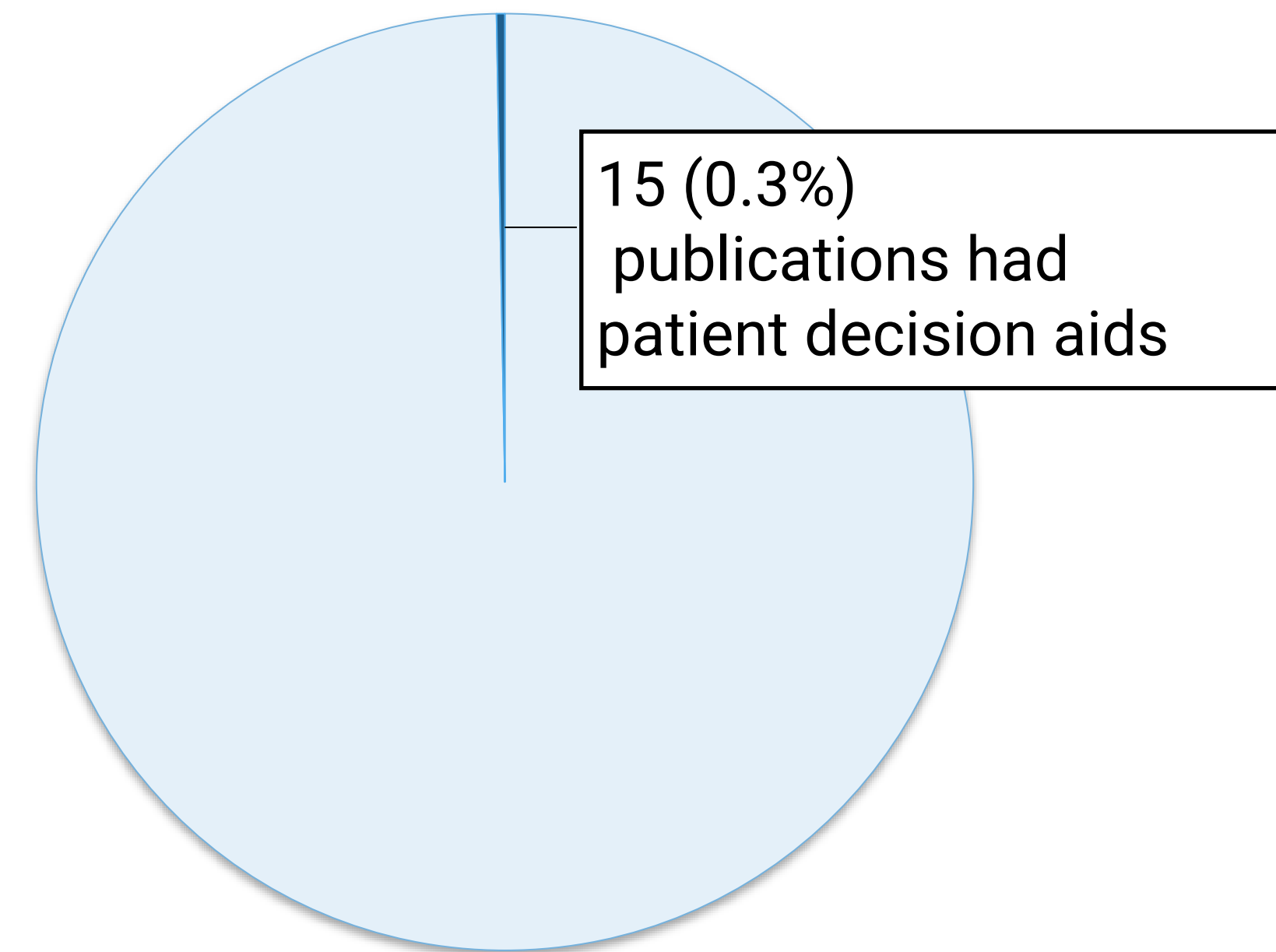
HCPs can support shared decision making among their patients with hematologic malignancies by using decision aids prior to, during, and/or after visits



Patient Decision Aids Increase Patient Satisfaction

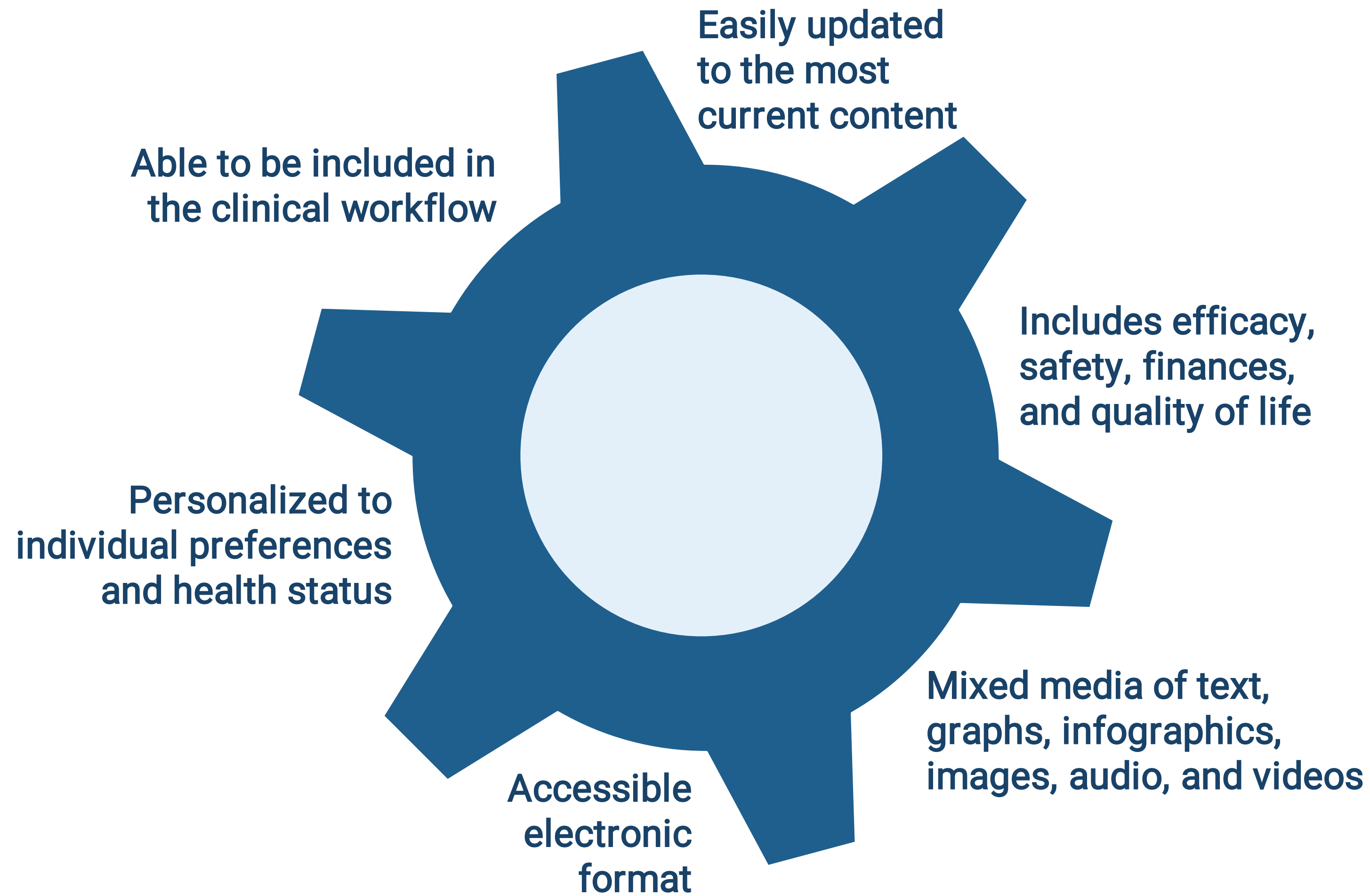
- Using PRISMA criteria in a systematic review, 5281 studies, abstracts, and clinical trial protocols were screened for involvement of patient decision aids for adult patients with hematologic malignancy
- Only 15 publications out of the 5281 screened had patient decision aids (figure)
 - Only 3 out 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 Shared 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

Testing for risk factors may inform treatment options

First-line Therapy Options

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

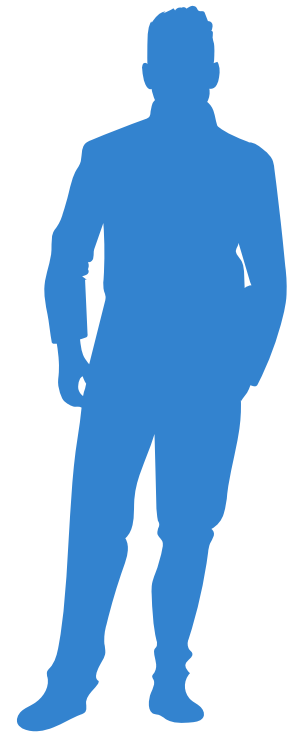
R/R Therapy Options

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

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

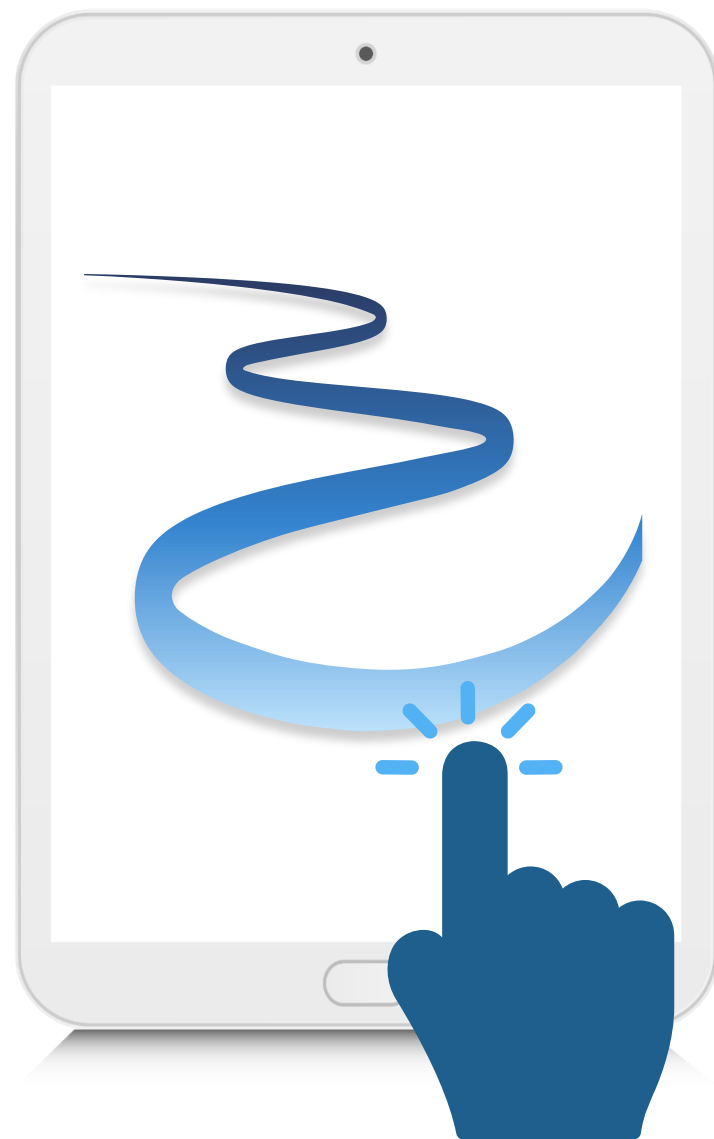
^aRanked by how HCPs think what their patients would prioritize.
HCP, health care provider; MCL, mantle cell lymphoma; R/R, relapsed/refractory.
LeBlanc TW, et al. *Blood*. 2015;125(23):5634.



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

HCP, health care provider; MCL, mantle cell lymphoma.

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

HCP, health care provider; MCL, mantle cell lymphoma; R/R, relapsed/refractory.

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/>.



CHAPTER 6: Overcoming Barriers to Shared Decision Making in CLL

Shared Decision Making May Help Patients Navigate the Complexity of Emerging Treatment Options for CLL



CLL¹

Diagnosis

- Many patients are asymptomatic at diagnosis when observation is the standard of care
- Consider surveillance when discussing treatment options

First-line therapy options

- Therapy is often necessary once disease is symptomatic
- Testing for risk factors along with prognostic scoring may help inform treatment options

R/R therapy options

There are several types/combinations of therapy options based on the patient's response to previous line(s) of therapy, including progression, timing, and/or tolerance

Effective new treatments with unique safety profiles and modes of administration (eg, IV vs oral) in CLL have emerged in recent years, creating an opportunity for patients to contribute their personal preferences toward their care^{2,3}

CLL, chronic lymphocytic leukemia; IV, intravenous; R/R, relapsed/refractory.

1. Shadman M. *JAMA*. 2023;329(11):918-932. 2. Rocque GB, et al. *Transl Behav Med*. 2018;8(2):175-182. 3. Laurenti L, et al. *Hemasphere*. 2022;6(9):e771.

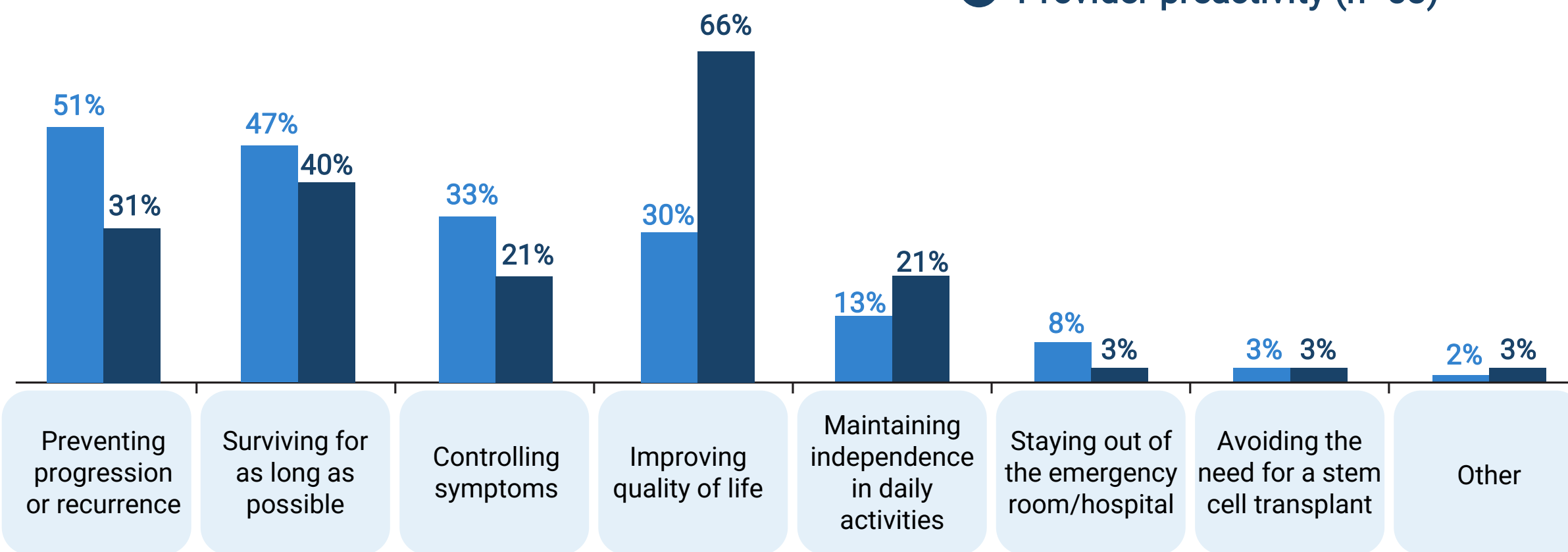
HCP and Patient Perceptions Differ on Key Decision Determinants for Patients With CLL



- In a US study from 2020 to 2021, patients with CLL and their HCPs across 12 oncology centers engaged in virtual, educational sessions and discussed their preferences, experiences, and concerns

Patient question: What are your top 2 goals for CLL treatment?

Provider question: What do you believe are the top 2 goals for CLL treatment among patients at this session?



Patients' perceptions

The patient's main challenges with CLL care include:

- Managing side effects
- Understanding treatment options
- Watching and waiting
- Financial concerns
- Emotional components when undergoing treatment

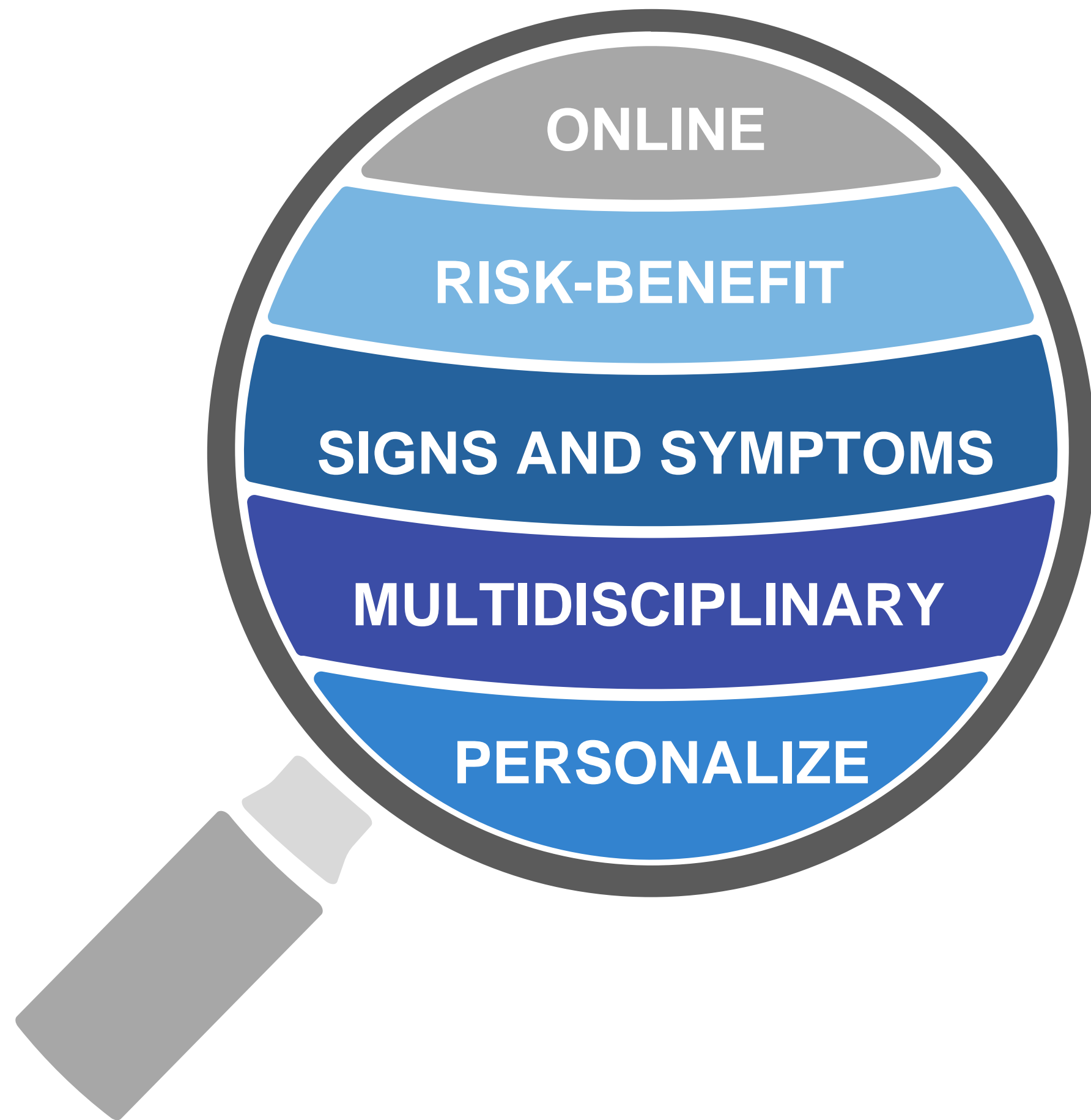
Providers' perceptions

Providers believed their patients' main challenge with CLL care was worrying about and/or difficulty **managing side effects**

Collaborative education can support increased knowledge, communication, and understanding between patients and providers, ultimately leading to shared decision making in CLL

CLL, chronic lymphocytic leukemia; HCP, health care provider.
 Davids MS, et al. Presented at: American Society of Hematology; December 10-13, 2022; New Orleans, LA. Poster 2225.

Patient Decision Aids May Improve Patient Satisfaction and Management of CLL^{1,2}



Utilize an online tool

Online tools for CLL have been shown to improve patient satisfaction, but include a printable option to increase the reach to patients and caregivers¹

Provide a risk-benefit profile on treatment options

A careful risk-benefit analysis of treatment options, including efficacy, safety, and treatment-related quality of life is essential to incorporate patient preferences and ensure adequate CLL education^{3,4}

Highlight the common signs and symptoms of CLL

Providing further education on the signs and symptoms of disease progression across lines of therapy may improve the management of CLL as HCPs highly rate this in their decision making^{2,4}

Educate multidisciplinary teams

Educating across nurses, APPs, and HCPs improves the shared decision making process and patient participation²

Personalize to consider disease characteristics

HCPs differ in their treatment recommendations for patients without *del(17p)* and *TP53* mutations¹

Educational materials are available online to foster learning among patients, caregivers, and medical teams⁵⁻⁷

APP, advanced practice provider; CLL, chronic lymphocytic leukemia; HCP, health care provider; R/R, relapsed/refractory; TP53, tumor protein 53.

1. Topping RP, et al. *Blood*. 2020;136(suppl 1):40. 2. Rocque GB, et al. *Transl Behav Med*. 2018;8(2):175-182. 3. Laurenti L, et al. *Hemasphere*. 2022;6(9):e771. 4. Ackbarali T, et al. Presented at: American Society of Hematology; December 10-13, 2022; New Orleans, LA. Poster. 5. Leukemia & Lymphoma Society. Accessed October 12, 2023. https://www.lls.org/sites/default/files/2023-06/PS48_CLL_Guide_2023.pdf. 6. Lymphoma Research Foundation. Accessed October 12, 2023. https://lymphoma.org/wp-content/uploads/2022/03/LRF_Factsheet_Chronic_Lymphocytic_Leukemia_Small_Lymphocytic_Lymphoma.pdf. 7. Leukemia & Lymphoma Society. Accessed October 12, 2023. https://www.lls.org/sites/default/files/2022-02/PS151_Discussion_Guide_Professionals_final.pdf.



Chapter 6: Key Takeaways

- Emerging treatments for CLL with unique safety profiles and modes of administration create an opportunity for patients to contribute their personal preferences toward their care^{1,2}
- Patients' input is essential to customize decision tools and educational materials for their individual needs since their decision determinants and educational needs may differ from other patients and those of HCPs³
- When providing online educational material and engaging in shared decision making with patients, consider providing a risk-benefit profile of treatment options, highlighting the signs and symptoms for patients to track, educating the full medical team, and personalizing the decision aid²⁻⁵

CLL, chronic lymphocytic leukemia; HCP, health care provider.

1. Rocque GB, et al. *Transl Behav Med.* 2018 Mar 1;8(2):175-182. 2. Laurenti L, et al. *Hemasphere.* 2022;6(9):e771. 3. Davids MS, et al. Presented at: American Society of Hematology; December 10-13, 2022; New Orleans, LA. Poster 2225. 4. Topping RP, et al. *Blood.* 2020;136(Supplement 1):40. 5. Ackbarali T, et al. Presented at: American Society of Hematology; December 10-13, 2022; New Orleans, LA. Poster.



SUMMARY



Summary



- Shared decision making occurs when an HCP and patient work together to align on a health care decision that is best for the patient¹
- Both patients and HCPs may benefit from shared 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 decision making may help better align treatment decisions with patients' values and preferences⁶⁻⁸

HCP, health care provider.

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