



Conversation Guide and Manual for Identifying Patients' Health Priorities

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Project overview I Overview of Purpose

The purpose of this intervention is to elicit patients' values and health goals, empower them to become more engaged partners in their health care, and provide their clinicians with information to align their health care with the patient's health goals and care preferences. The patient is the expert in what matters most to them; their providers are the experts in how to help the patient get there.

Your role as health priorities facilitator is to walk the patient through the following process:

1. **To help the patient express their values (step 1).** Values are the things that matter most for the patient. Values tend to remain stable even with life and health changes, and will directly lead to the patient's goals and health care preferences. Common values are things like family or friends, spirituality, hobbies, independence, etc.
2. **To help the patient establish health outcome goals (step 2).** SMART health goals (specific, measurable, actionable, realistic, and time based) are best. Additionally, the best goals are activities that are consistent with the patient's values and what the patient most wants to be able to achieve. For example, a value of family might lead to a goal of being mobile enough to attend family outings. A value of spirituality might lead to a goal of managing their fatigue to be able to attend church.
3. **To help the patient recognize how their health and health care helps or hinders the achievement of these outcome goals (step 2).** For example, a goal of being mobile enough to attend family outings may be hindered by arthritis, but helped by prescription arthritis medication. A goal of being able to attend church may be helped by using a walker, but hindered by using oxygen. In this process, you will also assess for healthcare burden (healthcare activities interfering with goals).
4. **To help the patient express care preferences and make decisions on health tradeoffs (step 3).** *Care Preferences* are what health care activities the patient is willing and not willing to do to achieve his/her health goals. For example, a patient with mobility issues may be willing to try physical therapy, but not surgery. *Tradeoffs* are when the patient needs to balance or exchange one thing or event for another. Tradeoffs may be between: 1) one desired outcome or another (e.g., prioritize working on mobility vs. pain control right now); 2) a desired outcome and what the person is willing and able to do or accept to achieve the desired outcome (for example, the patient may decide that taking NSAIDs for their arthritis helps with mobility, and they are willing to accept the increased risk of stroke).
5. **To help the patient communicate those goals, care preferences, and tradeoffs back to their health care team and to help patients become active participants on their care team (step 4).** The purpose of this process is to promote a partnership between the patient and their health care team through proactive communication methods to help the patient meet their goals. Patients learn how to communicate with their healthcare team, and create a personalized summary of goals and health care preferences to bring to their next primary care appointment. Throughout the intervention, remind the patient to share the information discussed with their health care team. You may even suggest helpful ways to word statements or start the conversation. Through patient activation and strengthening patient-clinician partnerships we hope to achieve alignment of health priorities to current treatment.
6. **To help the patient plan for health care changes based on their health trajectory (optional step 5).** Health trajectory is how a person's health and functioning will likely change in the future. As their health changes, certain goals may become more or less realistic, and care preferences may change as well.

Project overview | Practical Information

The intervention consists of the following 5 steps:



Overview

Steps 1—4 are covered with every patient. Step 5 is a flexible session that is tailored to a patient’s individualized needs and circumstances. Each is designed to take approximately 20 minutes, although some patients will grasp these concepts right away and identify their values quickly, others may need help and additional time. You can complete a single step or two steps each time you see the patient. The steps are structured, yet we encourage flexibility in order to meet each patient’s needs. As a result, the exact nature of the intervention you deliver may vary from patient to patient.

Encourage the patient to include any caregivers and/or family members who are important to him/her. These individuals will both help construct and be privy to the patient’s health goals and care preferences. However, remember that this intervention is focused on the *patient’s* goals, not their caregiver’s.

Some patients may not want to write in their workbook because they feel overwhelmed or they have physical restrictions such as arthritis or tremors. You can transcribe the patient’s ideas in the workbook for them if they are willing; otherwise, you can discuss the questions verbally. Guide them through the process using the prompts and questions. At a minimum, the only sheet that *must* be filled out is the Summary of Health Priorities on patient workbook page 21. Patients will bring this sheet to their next primary care appointment, in order to spark a conversation about aligning healthcare to their goals and preferences. Tips for starting this conversation are on the back of this sheet (page 22 in the patient manual). The information obtained in the intervention should also be integrated into the patients’ electronic medical records using a standardized template (provided; see instructions on p. 31 of this facilitator manual).

STEP 1

STEP 2

STEP 3

STEP 4

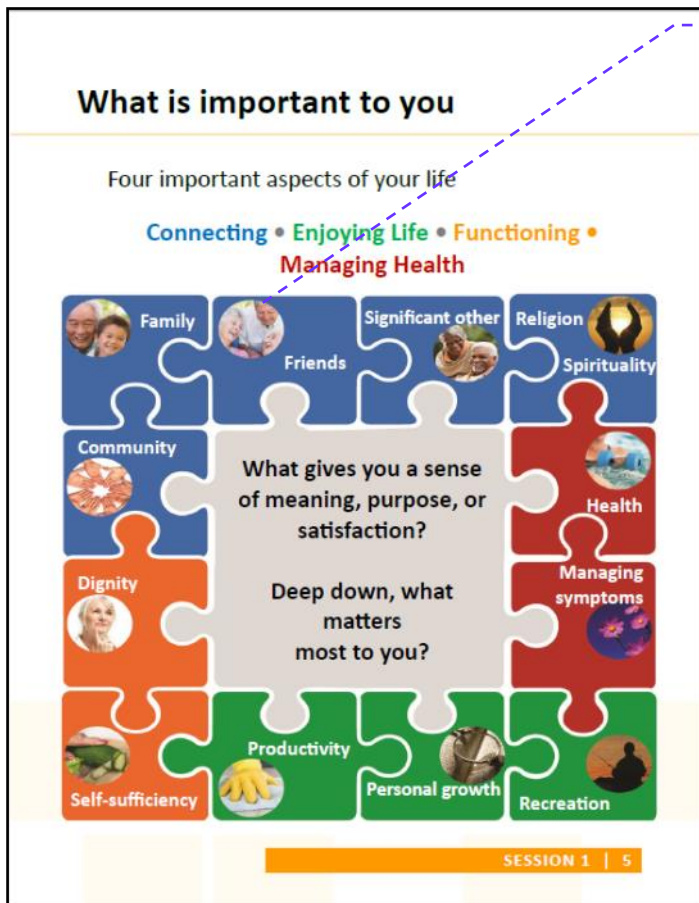
STEP 5

Project overview | Tips for Guiding the Conversation

- Active listening is an important skill for ensuring that you help patients identify their own values, goals and care preferences. Active listening means using non-verbal cues like nodding and appearing interested, and verbal cues such as summarizing what the patient has said to ensure you understand.
- The most important thing you can do as the facilitator is listen to what the patient is saying and watch where he/she “lights up.” Their voice and body language may show you what is most exciting and meaningful to them, and then you can follow up by asking more about these activities and how their health relates to them.
- These sessions are never completely linear. You may need to circle back or jump ahead as a patient brings up an important issue. On the other hand, sometimes patients may go off topic. You may listen briefly and sympathetically and then redirect them back to the topics at hand by saying something like: “That family conflict sounds really stressful! But I want to make sure we save time to talk about your goals.”
- Sometimes patients will be confused about what we are asking. They likely have never had to identify values, goals, or care preferences in this way before. You may try to provide an example (e.g., the Dave example from the patient manual) or suggest an answer based upon something the patient has already said (e.g., “I remember you mentioned that a medication you’re taking helps with shortness of breath but causes you to go to the bathroom all night. That sounds like a tradeoff to me. What do you think?”
- Remind patients that there are no right answers and they can feel free to be honest with you. This is about getting the healthcare *they* want, not what their health care providers or family want.
- At each step in the process, validate what the patient tells you. Validation means that you convey to the patient an accepting, non-judgmental attitude, and that you recognize the validity, worth, or truth of what they are saying. Example validation language includes: “You’re overwhelmed by all of your healthcare activities. That makes a lot of sense.” “I can understand why you’d rather not take any more medications! You’re already taking a lot.” or “That sounds really frustrating!” Validation language conveys to the patient that this is an accepting place to express whatever opinions and preferences they have, which is crucial to eliciting their true goals and care preferences.
- Your role as a facilitator is to stay objective. There may be times that patients might want something that you disagree with or think is the wrong direction for them, but your role as a facilitator is to help each patient achieve their goals and live according to their values to the degree possible.

How to use this manual:

This manual follows the steps in the accompanying patient workbook, page by page, with screenshots of the accompanying patient manual pages. It is meant to be used in conjunction with that workbook. This assumes that you have completed training in Value-based Health Priorities facilitation and understand the concepts and purpose of the health priorities elicitation. Refer back to the facilitation training for more in-depth discussion of the concepts.



These boxes will give instructions on what to say or how to help the patient with the exercises on the page.

“Suggested language to use with patients is presented in blue.”

Of course, feel free to use whatever language is most natural to you and understandable to the patient.

Tips:

- o Helpful tools for the facilitator will appear in these orange boxes.

INTRODUCING THE PROGRAM: PAGE 2

Before we start going through the steps, it is important to make sure the patient understands the purpose of this intervention. Having patient buy-in is crucial to engagement in the process. Additionally, you should identify your connection with their current healthcare providers, making sure the patient understands that you are part of their healthcare team and will be communicating with their healthcare team, and also that *they* are an important part of their healthcare team. Make sure you give the patient time to ask questions.

The purpose of this program

To make sure your health care lines up with *your* priorities.

- Step 1 • Discuss what matters to you.....p. 3
- Step 2 • Set your goals and examine how your health care lines up with your goals.....p. 8
- Step 3 • Make decisions about tradeoffs in your health carep. 14
- Step 4 • Talk with your health care team about your goals and preferences.....p. 17

“I work with your health care team and they want to know more about what matters most to you in your life and your health. The more he/she knows your goals and understands your feelings about your health and your health care, the better he/she can help you make the best choices about your care. It’s about finding what works best for you. In Step 1, we will start with what matters to you in life. In Step 2, you will set goals. In Step 3, you will discuss how your healthcare helps or doesn’t help you meet your goals. In Step 4, you will state your health care preferences, and finally, in Step 5, we will work on communicating those with your health care team. Do you have any questions for me before we get started?”

STEP 1: PAGE 3

Direct the patient to turn to page 3 to begin step 1. Introduce the step, summarizing the bullet points on page 1.

Step 1

Exploring what matters

In this chapter, you will:

- **Identify** what matters most to you in your life and health
- **Describe** what you want your healthcare to do for you

CHAPTER 1 | 3



“First, we’re going to talk about what matters most to you, and what you want your healthcare to be able to do for you.”

STEP 1: PAGE 4

The first step is to identify the patient’s values. Direct them to look at the diagram on page 4 for examples of possible values. Provide a few examples, so they understand what you mean by values. Sometimes people have a difficult time understand the word “values”. If so, use “*what matters most to you*” or “*what’s most important to you in life*”.

What is important to you

Four important parts of your life:

Connecting • Enjoying Life • Functioning • Managing Health

Family Friends Significant other Religion Spirituality

Community Health

Dignity Managing symptoms

Independence Productivity Personal growth Recreation

Deep down, what matters most to you?

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“First we’re going to start with what’s most important to you, or what you might call values. Look at this picture—it has some examples of what matters most for different people, like family, friends, independence, recreation, or spirituality. What comes to mind when I ask, ‘What matters most to you?’”

STEP 1: PAGES 5 & 6

Page 5 introduces an example character that patients will follow throughout the workbook. On page 6, Dave lists what matters most to him. You can briefly go through this example so that patients understand what we are asking for when we discuss values. Remind patients that everyone has their own values, and there are no right or wrong answers to these questions.

“This is an example of another patient who went through this process. We are going to go through this just as an example. Remember that everyone has their own values—there are no right or wrong answers.”



Meet Dave! He’s a 74 year old widower with diabetes, heart disease, and arthritis.

You’ll follow Dave’s example throughout this book to help you understand how to answer the questions.

CHAPTER 1 | 5

What matters most: Dave’s Example

Write your answers, OR just say them.

Connecting

Family, friends, spirituality/religion, community

Which relationships or connections are most important to you?

My daughter, my dog, friends from church

Enjoying life

Recreation, hobbies, play, personal growth, learning, being productive

What brings you the most enjoyment or pleasure?

Taking walks with my dog, going to baseball games

Functioning

Taking care of yourself, being independent, not having to depend on others

When taking care of yourself, what is most important to you now?

Being able to walk, not being dependent on others

Managing health

Quality and length of life, mind and body health, managing pain and fatigue

What do you hope your health care can do for you?

Allow me to live by myself as long as possible

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STEP 1: PAGE 7

Next, we ask the patient to identify their own values. Go through each of the four domains to assess the patient's values in that area using the questions provided. If the patient has trouble writing, offer to write for them or have them say the answers out loud.

Clarifying values early on will help the patient in step 2 identify meaningful goals that are consistent with their values. In later sessions, patients may identify goals that are not realistic; if the facilitator is aware of the value underlying the goal, the facilitator can help the patient identify other goals that reflect the value.

What matters most: Your turn

Connecting
Family, friends, spirituality/religion, community
Write your answers, OR just say them aloud to your coach.
Which relationships or connections are most important to you?

Enjoying life
Recreation, hobbies, play, personal growth, learning, being productive
What brings you the most enjoyment or pleasure?

Functioning
Taking care of yourself, being independent, not having to depend on others
When taking care of yourself, what is most important to you now?

Managing health
Quality and length of life, mind and body health, managing pain and fatigue
What do you hope your health care can do for you?

CHAPTER 1 | 7

Additional prompts if necessary: *"If you had to name the three things that matter most to you in your life, what would they be?"*

Connecting: *"Who are the most important people in your life? How often do you get to see them? What kinds of things do you do together?"*

Enjoying Life: *Which activities do you do that you find so important and enjoyable that you can't imagine living without them? What brings you enjoyment or comfort?*

What could you do before that you would like to do now? What do you do now that you'd like to be able to keep doing?

Functioning: *"What does a good day look like and what does a bad day look like? When it is a good day, what goes right? What kinds of things are you able to do/not able to do? How do you feel about asking for or accepting help?"*

Managing health: *In what ways do your health conditions and treatments limit your ability to do what matters to you?*

Tips:

- A patient may only be able to articulate one particular valued life activity or ability that is at the forefront of their mind, but that doesn't mean the others are not as important. It is important to systematically ask about all the valued life activity / ability domains to make sure the patient has the opportunity to identify activities in many areas. It is also fine if a patient articulates only a few values initially. It also may be that they have more than one goal linked to a single value.
- Sometimes patients delve immediately into their health or bothersome symptoms. This can be a good place to start, as you will learn much about their care preferences from what they describe. Learning about their perception of their health status and their treatment burden is critical in identifying care preferences. Pay attention to the health care burden the patient describes. Note this information for the later step (step 3) where you assist the patient in identifying care preferences. Burdens they describe could be tasks they would prefer not to do.
- If the patient does start with their health care burden or problems, it is important to remember that their health outcome goals are based on their values—what matters most to them. You do want to eventually refocus the conversation with the patient back to expressing their values, you may want to use the following prompts:

Prompts: “What would you be doing if you didn’t have to do X or didn’t have this problem?” or

“In what ways do your health conditions and treatments limit your ability to do what matters most to you?”

- During this exercise, you might obtain clues about tradeoffs they are facing. Make a mental note, as this will help you identify goals and care preferences later.
- If you feel the patient is telling you what they think you want to hear:

Prompt: “I want to make sure I understand what matters to you, not what others (like your loved ones or health care team) think you should care about. There are no right or wrong answers to these questions. What’s most important is that you choose things that are heartfelt and meaningful to you.”

STEP 2: PAGE 8

Direct the patient to turn to page 8 to begin step 2. Summarize the bullet points on page 8.

Step 2

Doing what matters

In this step, you will:

- **Set** meaningful health goals
- **Discuss** how your health or healthcare helps or gets in the way of those goals

Meaningful health goals....

...are anything that you hope to achieve through your health care.

“In this step, we are going to understand your health goals, or what you want to be able to do. Then, we are going to discuss what’s going well with your healthcare and what’s not going so well.”



STEP 2: PAGE 9

Explain that in order to set goals, we need to know what we mean by health goals, and what good goals look like. You may be more familiar with the SMART goal framework (specific, measurable, actionable, realistic, and time-bound)—but we have found it necessary to simplify this for patients. Thus, we use the bullet points below.

Doing what matters

Meaningful health goals are:

- **Based on values:** What matters to *you*.
- **Realistic:** Something you are able to do, keeping in mind your current health.
- **Specific:** Includes exactly what to do.
- **Flexible:** Can be changed over time as needed.

“First, we need to understand what we mean by goals, and what a good health goal looks like. A health goal can be something you want to keep doing, or something you would like to be able to do more of. For example, a health goal might be something like: ‘Be able to walk enough so I can go to family outings.’ or ‘Manage my arthritis enough to keep knitting.’

In addition to having goals based on our values, we also want goals to be realistic and specific so that your health care team can work with you on making sure your healthcare is focused on achieving that goal. And it’s OK if these goals change over time—we will be flexible as your health changes.”

STEP 2: PAGE 10

We start here by reviewing values from the prior step and asking the patient to identify activities that they already do or would like to be able to do to live out that value. This may not yet take the shape of a true SMART goal, and that's OK—at the bottom of the page are prompts to facilitate a discussion about whether they are currently able to do that activity, and whether it's specific and realistic. This discussion should help shape the goal into a more 'SMART' format. For example, a patient who identifies that family is an important value for him might state that he wants to be able to play with his grandchildren. Through discussion, he may identify that he means being able to play their favorite videogames (a more specific goal) and that this is realistic for him given his health.

Doing What Matters

Look back at *what matters most* to you on p. 7.

Discuss:

- What activities do you want to be able to do that reflect what is important to you? How has this been going lately?
- What would you want to be doing more of? Have you been doing it lately?

Check:

- Is the activity specific?
- Is the activity realistic?



"We've already talked about what matters most to you in your life. Based on what you said last time we met, that was (summarize). Now let's talk more about how you would show that you are living out those important things. Let's identify activities that you can do or want to be able to do that reflect what is important to you."

STEP 2: PAGE 11

By this point, you should have been able to identify goals that are meaningful (connected to values) and realistic. We are not setting goals in the behavioral sense but rather identifying health outcomes that patients want to achieve that will be used in decision making between patients and their clinicians. On this page, patients can write down their revised goals, after any discussion from the prior page about whether their goals are specific, realistic, etc. These goals should be actionable health goals that will aid their health care team in prioritizing treatment. Again, Dave provides an example. At the bottom of the page, we ask patients to elaborate about how their health gets in the way of doing these goals.

Set specific goals

Dave's example

Manage arthritis enough to be able to walk my dog at least 10 minutes a day

Your Specific, Realistic Goals:

A. _____

B. _____

Does your health get in the way of those goals?

CHAPTER 2 | 11

“Given everything we’ve talked about, let’s set two specific, realistic goals for things you want to be able to do. You can see Dave’s example here.”

“Now, does your health get in the way of those goals? How?”

Tips for Goal Setting:

- It is important to make sure the patient's goals are SMART! (specific, measurable, actionable, realistic, time-bound). To do so, you may ask questions like ***“What would you do specifically? For how long? How often?”***
- To determine if goals are realistic, review them briefly with the patient. Try asking ***“When was the last time you were able to do this activity? Or “Maybe we need to work our way up to that—what do you think is a good place to start?”***
- If a patient has difficulty articulating goals, provide examples of meaningful goals (Example: if the value is being physically active, the goal might be walking for 20 minutes/day); or, return back to their values and ask them how they would like to live that value: ***“You told me that your relationship with your grandchildren is very important to you...what kinds of activities do you do together or would like to be able to do together, if your health let you?”***
- If a patient sets an unrealistic goal, find out why they want to do those things—what value is that tapping? And set a different goal that addresses the same desire or value. For example, if a patient sets the unrealistic goal of taking the grandchildren to the park (patient is housebound), a different goal that addresses the same value might be being able to play boardgames or read with the grandchildren.
- Goals should always be linked to values. Facilitators can ask about how a goal is related to the values previously identified.
- If the patient's goals are about avoiding a feeling, condition, or state (e.g., “Stop worrying that I will be in pain if I leave my home,” or “I don't want to feel tired”), work to revise these goals to become more action- or outcome-based goals. For example, ask ***“What would you be doing more of if you were not worrying about pain?” “What would you do more of if you weren't so tired?”***
- Goals don't have to be about starting a new behavior. They can also be aimed at maintaining a current behavior: ***“Your goals for the future may involve continuing to do what you currently do in your daily life, or may involve expanding what you are able to do. What do you already do that you'd like to keep doing in the future? What do you not do now, but would like to start doing in the future?”***
- The right-hand side of the chart walks through the effects of health on the patient's ability to achieve their goals. This can provide valuable information about care preferences and tradeoffs that will be used in step 3. Try asking: ***“How does your health get in the way of... X (goal)?”***

STEP 2: PAGE 12

Now, we discuss how the patient’s healthcare is helping and not helping meet those goals. Assess for healthcare burden and healthcare preferences—concrete information that can be communicated back to their health care team to shape the future care they receive. Emphasize that there are no right or wrong answers—their preferences are their own. Remember—it’s very important for the health care team to understand patients’ honest statements about what is helpful and what is burdensome about their care. These care preferences are often what determines how adherent patients are to the healthcare team’s recommendations. If the team is worried about patient adherence or patient motivation, then they have to have a compassionate understanding of patients’ care preferences. On p. 12, we start with asking about what parts of their healthcare are working. Go through each category of tasks and ask which *they think is working well or helps them achieve their health goals*.

Your Healthcare

Your healthcare should help you reach your goals. For example, a medicine might help you have more energy to do the things that are important to you.

What healthcare is helping you meet your goals?

Medicine:

Self-care tasks (like diet):

Blood tests, X-rays:

Doctor and other medical visits:

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“We want your health care to help you do the things that matter to you, so let’s talk about what parts of your healthcare help you achieve your goals. For example, maybe you are really noticing that a certain medicine helps you feel better, which gives you the energy that you need to do what is important to you.”

“Which parts of your health and healthcare are going well? ”

“What things are really helping you?”

STEP 2: PAGE 13

On this page, we discuss the opposite side of the coin—parts of their healthcare that are NOT helping them meet their goals. Assess for healthcare burden and healthcare preferences—concrete information that can be communicated back to their health care team to shape the future care they receive. Go through each category of tasks and ask *which parts of their healthcare they don't think helps or is difficult, burdensome, or causes problems*. Sometimes patients are worried about being seen as non-compliant if they object to a treatment. The facilitator can alleviate this concern by acknowledging it: “This conversation is about what really helps you—it’s OK to tell me what you really think.” At the end of this discussion, briefly discuss how it will be important to communicate this information back to their health care team so that they can receive care that works for them.

Is your health care helping you meet YOUR goals?

We ALSO want to know what is not going well in your healthcare, including things that don't help you meet your goals, things you are unable to do, or cause problems. For example, a medicine that has bad side effects, not being able to check your blood sugar, or too many tests.

What about your healthcare is making it difficult to meet your goals?

Medicine:

Self-care tasks (like diet):

Blood tests, X-rays:

Doctor and other medical visits:

CHAPTER 2 | 13

“Is there anything in your healthcare that is making it difficult or not helping you meet your goals?”

“Which parts are burdensome or bothersome?”

“Are there any healthcare activities that you think aren't helping you?”

“Do you feel that self-care tasks or treatment gets in the way of what you look forward to doing?”

To spur discussion, you *may* need to ask specific questions about each area, such as: ***“What time of day do you take your medicines? Does anyone help you with them? Are you noticing any side effects? Do you take insulin or check your blood sugar? How is that going? How often do you have medical appointments? Are you on a special diet? How is that going?”***

STEP 3: PAGE 14

Direct the patient to turn to page 14 to begin step 3. Summarize the bullet points on page 14. The purpose of this step is to understand what is burdensome or bothersome to the patient, so that this information can be funneled back to their clinicians, who can engage in shared decision-making about which treatments are worth it to the patient, given the patient's goals.

Step 3

Understanding health tradeoffs

In this chapter, you will:

- **Communicate** the benefits and burdens of your healthcare.
- **Discuss** what you are willing and able to do to meet your goals.
-



“In this step, we are going to spend some more time talking about balancing the benefits and burdens of your healthcare, or what we call health tradeoffs.”

STEP 3: PAGE 15

On this page you will explain the concept of the benefits and burdens of healthcare. Ideally, you will provide one or two examples (see box below). You can also ask the patient for any examples that come to mind in their life.

The benefits and burdens of health care

When you have more than one health problem:

- Certain health care activities (like taking medicines) may make some things better while making others worse. This is called a tradeoff.
- Your health care team may not know understand how much burden certain activities are, or which of your health goals are most important for you.
- Are any treatments more burden than benefit for you?
- Think about the future: What do you think your health will look like in the next year?



You decide which tradeoffs make sense
in your life!

CHAPTER 3 | 15

“I want to talk about the benefits and burdens of healthcare. Here’s one example: A patient with diabetes may need to reduce how many sweets they eat. That’s the burden. But reducing sweets may keep them healthier longer. That’s the benefit. Everyone gets to decide for themselves which benefits are worth the burdens. We call that a tradeoff.”

“Another example is that a patient with sleeping problems may take a sleeping pill that does help them sleep (benefit) but makes them groggy the next morning (burden).”

“It would be great if you could reach your goals without treatments that are hard or uncomfortable, but that is not always possible, so you may have choices to make about which treatments are worth the added burden.”

“Your health care team may not know how much certain burdens bother you. If they understand better, they can discuss the pros and cons and make treatment decisions with you.”

STEP 3: PAGE 16

After exploring the benefits and burdens they noticed on the prior page, here we are formalizing the health care activities patients are willing to do and prefer not to do. Ask systematically about each possible type of tradeoff (eg, medications, appointments, self-care activities like diet or blood pressure monitoring, etc). This information will be funneled back to the patient's health care team to help them understand the patient's preferences.

When treatment burden has been discussed, then it can be used as an opportunity to assess the individual's understanding of what that treatment is supposed to do for them and what it would mean if they were no longer doing it or doing less of it. For example, not wanting to check blood sugars may result in a hypoglycemic reaction, but they may be willing to take this risk to avoid the hassle of blood sugar checks. As these situations arise in your visits, try to point them out to the patient and see if they recognize these tradeoffs. These will be helpful points for their health care team to help them navigate care choices.

Making tradeoffs you can live with

Your tradeoffs

What are you willing and able to do?
(Examples: adding medications, scheduling more medical appointments, trying new treatments)

Dave's example:

- A. I'm willing and able to: Take a water pill that makes me have to use the bathroom more often.
- B. I'm willing and able to: Stick to my prescribed diet.
- C. Things I'm unable to do/cause problems/not helpful: Using insulin for diabetes causes problems because of the shots.

A. I'm willing and able to: _____

B. I'm willing and able to: _____

C. Things I'm unable to do/cause problems/not helpful: _____

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"It's important to decide what you are willing put up with in order to get what matters most to you.

It's also important for your health care team to know what is most important to you, and what you are willing to put up with, so you can make the best decisions together.

Given what we've talked about so far, what parts of your medical care are you willing to do even if it causes some burden? First, think of medicines. Now, what about diet, other types of treatment, appointments, etc.?

And what parts of your medical care do you think are not worth the added burden? What health care activities would you prefer not to do?

Tradeoffs can change over time as things change in your life, so let your team know if things are becoming too much."

STEP 4: PAGE 17

Direct the patient to turn to page 17 to begin step 4.

Step 4

Talking With Your Health Care Team

In this session, you will:

- **Discuss** the importance of letting your health care team know your goals and health care preferences.
- **Learn** tips for communicating with your health care team.
- **Create** a Health Priorities Summary sheet to bring to your health care team.



“In this step, we are going to talk about how to communicate your health care preferences when talking with your health care team, and how to be an active partner in making health care decisions. We will create a summary sheet of everything we’ve talked about to bring to your next primary care appointment, and practice how to start that conversation.”

STEP 4: PAGE 18

Discuss with patients that knowing what matters most helps their health care team recommend the care and treatments that are most focused on what they want from their health care. This will help ensure that their care is aligned with both the health outcomes that matter most to them and with health care tasks that they are willing and able to do to achieve these outcomes.

Why is communication important?

- Good communication can help you and your health care team decide *together* what's best for you.
- Of course, communication is a two-way street, but the more you communicate with your health care team, the better they will be able to align your care with what is most important to you.



After your medical visits, share the discussion about your goals and your health care plan with your family.

“Your health care team needs to know what is most important to you so you can work together to make the best decisions for you.

We are hearing from many patients that doing everything they are supposed to do is too burdensome. When you share your goals with your care team, you and your team can design care that supports your goals, and provide the least burdensome care that can help you be as healthy as possible. It will also help us to make sure that all your providers are on the same page in regards to caring for your multiple conditions.”

STEP 4: PAGE 19

Many people feel intimidated to bring up their opinions or ask questions when they have medical appointments. They may not know they can discuss their health goals and care preferences with their clinicians or that their clinicians want to know these. It is important to encourage the patient to share all the things they've identified in this process with their health care team. Additionally, you may ask extra questions to assess whether they have any difficulties speaking up (like embarrassment, being deferential, not understanding medical terms) or whether there are difficulties in patient-provider communication that could be addressed.

Working with your health care team

Talk openly:

- Let your health care team know your goals and health care preferences.
- What help do you need from your team to meet your goals?

Communication Tips

- Ask questions. When your health care team discusses treatment options, ask how the treatments could affect your health goals.
- Voice your preferences. Tell them what you are able to do and what you think is helping; and what is not helping or is bothersome.
- Be specific. For example, instead of saying "I don't like this medicine," Say: "This medicine makes me feel weak and dizzy."

"Here are some tips for good communication with your health care team. We want you to be able to communicate openly and be a part of your health care team. Before we go through these, how comfortable do you feel talking openly with your team about your goals and preferences?"

Tip:
If a patient is struggling with communication, consider talking through with the patient an important conversation they need to have with their health care team. You may suggest wording choices to help them convey their meaning effectively.

STEP 4: PAGE 21

This page is designed as a ‘tear out’ sheet for the patient to hand to the health care team at their next appointment. Although the information will also be placed in the patient’s electronic medical record, this sheet can remind both patients and providers and help spark conversation about the patient’s goals and care preferences. Guide them through completing this so that the information will be useable for their health care team. If necessary, you can go through the Dave example on p. 20.

Your Summary of Health Priorities

Bring this sheet to your next appointment to start the conversation about your goals and preferences.

Health Goals: What you want to be able to do

From page 12

Health Care Preferences and Tradeoffs

From pages 13 and 16

The one thing about my healthcare I most want to focus on is:

_____ so that I can do more of: _____ more often
or more easily.

Things I’m willing and able to do for my health:

Things I am unable to do/causes problems/not helpful:

“Now we are going to create a sheet to bring to your next appointment to summarize the things we’ve discussed, to start a conversation with your team. First, they need to know your goals.

Next, it asks ‘The one thing I want most to work on is ___ so I can ___:’ For example, you might say things like ‘The one thing I want most to work on is my shortness of breath, so I can play with my grandkids.’ Or you might say ‘The one thing I want most to work on is taking fewer medicines, so I can worry less about mixing them up.’

Next, we are going to list the things you are willing and able to do. Finally, we will list the things you are unable to do, cause problems, or are not helpful. For example, you might put things like ‘It’s not helpful to add more medications because I already have trouble keeping track of them.’ or “It causes problems to have too many appointments because my daughter has to take off work to drive me.”

Tips:

- **Introducing this page:**
 - "Often times when we go to medical appointments we are focused on what's wrong with us or what we can't do. Communicating what you can do and what your goals are will help you and your health care team create care plans that support your goals."
 - Tell patients that this is a comprehensive summary of their health goals and health care preferences, and that it can be used as a tool to facilitate conversation with clinicians and loved ones.
- **Health Goals section:**
 - The goals may be pulled from page 12, or may need to be slightly revised based on your conversations.
- **Health Care Preferences section:**
 - Make sure the second item, the one labeled 'The one thing I want most to work on' is something potentially actionable or realistic. For example, it may not be realistic to expect to completely eliminate pain, and asking for that may shut down the conversation with their team. If pain is the issue, try to phrase it as '**The one thing I want most to work on is *managing my pain so I can do (Activity X).***'
 - Encourage the patient to be completely honest. In the past, they may have agreed to certain treatments but not followed through on those (like taking certain medications) because they had difficulty telling their health care team that the benefits to them didn't outweigh the burdens. This is an opportunity to have input into discontinuing parts of the treatment plan they don't think are worth it, and to focus the health care team's attention on the functional goals that are most important to them (mobility, use of their hands, etc). Or they may find out that this treatment is likely to help them achieve their outcome goals so they need to decide if this outcome is important enough to put up with the burden.
- **Afterwards:** You should discuss how they might bring up these topics with their health care team or even role play what they might say to communicate this information. You might say something like "***Let's practice together! Take goal #1. How might you tell your health care providers about this?***"
- You may also need to problem solve how they might remember to bring this to their next appointment. For example, could they keep a copy with the appointment reminder card? Or take a picture with their phone so they have it on hand when needed?

STEP 4: PAGE 22

Conveniently located on the back of the ‘tear out’ sheet (page 21 in the patient manual) is a list of some example language to use when starting this conversation with their provider. You can review these in session with the patient and encourage them to select a few that might apply. Patients can practice the wording in session or with a family member. Some tips for this conversation are presented on the next page.

Tips for Talking with Your Healthcare Team

Example language to use:

- Now that you understand what’s important to me, can we work on a solution that would allow me to...
- I really don’t like...
- What concerns me most is...
- My main priority is making sure I can _____.
- Even if it’s uncomfortable, I’m willing to _____ if it helps me _____
- I’m willing to _____ if it helps me meet my goals.

Tips:

- Health care providers and teams respond to specific patient “asks and tells”. For example, help your patients learn to phrase things like: **“Since I want to be able to continue to go kayaking, will this medication cause dizziness?”** These statements emphasize the importance of linking the health outcome goals to care preferences—The one thing I want most to work on is this so that I can...
- Some patients need permission to discuss bothersome care, including side effects of medications, multiple clinician visits, unwanted or unnecessary procedures, and how certain care recommendations can affect current functioning. You can help provide that permission by reassuring the patient that their health care team wants to know these to be able to work towards a mutually agreeable solution.
- The patient’s perception of the information that their clinicians want to know may be narrow. As a goals facilitator we should reinforce that clinicians want to know what matters most to the patient to determine if their current care plan is helping or hindering achievement of what matters most to them.
- Encourage the patient to be as blatant and deliberate in statements as their comfort allows. Clinicians cannot act on subtleties. Through transparency, the patient-clinician partnership can be strengthened and space can be created for the patient to be candid with their health care team. Some example language might be: **“Your health care team wants to be able to link your care with your health goals, and they can only do that if they know what parts of your health care may be bothersome or getting in the way of achieving your goals.”** or **“Your health care team wants to know what matters most to you especially if your quality of life and current function are what you are concerned about.”**

AFTER YOUR PATIENT SESSION: EHR TEMPLATE

After completing page 21 with the patient, you will also complete a note in the patient’s electronic medical record documenting this conversation. This helps notify the patient’s medical team of their goals and healthcare preferences, so that the team can discuss these with the patient and take these into account. Notify or route the document to the patient’s care team.

Patient Name:		Date:	
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Patient Priorities Care: Health Priorities Template

Current Function and Support:

← Based on facilitator’s impression of patient

Health trajectory (Current understanding of how health will likely change over the next few years):

← Values from patient manual page 7

Matters most (Values):

SMART Health Outcome Goals

- 1.
- 2.
- 3.

← SMART Goals: from patient page 11

Helpful care: The medications, self-management tasks, clinical visits, tests, or procedures, that I think are helping me most with my health goals and I can do them without too much difficulty

- 1.
- 2.
- 3.

← From patient page 12

Difficult or bothersome care: The medications, self-management tasks, clinical visits, tests, or procedures that don’t think are helping my goals and are bothersome or too difficult for me. I would like to talk with my doctor about whether these are helping my goals. If not, can I stop them or cut back? If they are helping, is there a way to make them less bothersome or less difficult?

- 1.
- 2.
- 3.

← From patient page 13

Specific ask (One Thing): **Specific ask (One Thing):** The one thing about my healthcare I most want to focus on is *(fill in a health problem that you think is keeping you from achieving your health outcome goal OR the healthcare task that is most bothersome or difficult)* so that I can do *(desired activity)* more often or more easily.

← Specific Ask for health care team

Priorities Facilitator:		Phone/Email:	
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← Your name and contact information

STEP 5: PAGE 23

This is an optional step for patients who anticipate an upcoming change in their health or who have recently experienced a change that significantly impacted their health, functioning, or life expectancy. Common examples are surgeries, amputations, new diagnoses of cancer, etc. We recognize that as patients' health status changes, so too might their goals and preferences. For example, a patient who was previously focused on maintaining independence but recently received a lung cancer diagnosis may decide that freedom from healthcare burdens and minimizing suffering are now his priority. This step gives them a chance to discuss changes in their goals and preference and to communicate those to their health care team.

Step 5

Adapting to changes in your life and health

In this chapter, you will:

- **Discuss** any recent or upcoming changes in your life or health.
- **Think about** how your life and health goals may have changed
- **Create** an updated Health Priorities summary.



“In this step, we will discuss any changes in your life or health, how your goals may have changed, and create an updated summary for your health care team.”

STEP 5: PAGE 24

This section starts with summarizing the recent or upcoming change(s). You can discuss with the patient that as your health changes, so too can your values, goals, and health care preferences.

Adapting to changes

Recent or upcoming changes in my life or health:

Example: Dave had a minor stroke last month.

When you experience changes in your life or health, it's important to recognize that:

- What is most important to you may change.
- Some health goals may become less realistic, and may need to be changed.
- The health care activities you and your loved ones are willing and able to do may change.

STEP 5: PAGE 25

This page walks the patient through 1) how changes have affected or will affect their ability to live their goals, 2) whether their goals have changed, and 3) how their preferences have changed.

Adapting to changes in your life

What is most important in your life

How have changes affected the areas of life that matter most to you?

Dave's Example: *My stroke made it hard to walk my dog.*

Health goals

Have these changes influenced your health goals? If a goal is no longer realistic, how can you change it?

Dave's Example: *I can play fetch with my dog instead of taking her for a walk.*

Health care preferences

Are you working so hard to achieve a goal that doesn't feel worth it?
Have the activities that you are willing and able to do changed?

Dave's Example: *I am willing and able to do physical therapy so I can walk my dog better.*

Tips:

- Patients may also set new goals in this process. For example, if the recent change was a stroke, possible new goals may involve increasing ability to do self-care like bathing or dressing.
- Gently encourage the patient to be realistic. It can be hard to accept that goals that may have been realistic in the past may no longer be realistic. Large changes in functioning or life expectancy may suggest that it is appropriate to 'step down' the intensity of managing certain chronic diseases and focus instead on quality of life. For example, a patient with diabetes and terminal cancer may appropriately decide to have more flexibility in eating what they want.
- Encourage the patient to involve friends and family members. However, sometimes family members have different goals and want care that is inconsistent with patients' own goals and care preferences. Remember, the purpose of this intervention is to align healthcare with the patient's goals, *not* the family's goals. One way this intervention may help is by making the patient's own preferences clear to the family members.

