

Appendix F. Improving Methods of Incorporating Racial/Ethnic Minority Patients' Treatment Preferences Into Clinical Care: Enhancing the SHARE Approach

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Summary: The SHARE Approach, developed by the Agency for Healthcare Research and Quality (AHRQ), is a five-step process for shared decision making intended to provide guidance to providers about how to work with patients to make the best possible treatment decisions. It includes exploring and comparing benefits, harms, and risks of treatment options through meaningful dialogue about what matters most to the patient. SHARE is also intended to specifically support shared decision making through the use of patient-centered outcomes research (PCOR). Central to the SHARE approach is the concept that the best decision for the patient about what treatment to pursue will be one that takes into account the current evidence base about treatment effectiveness, the provider's knowledge and experience, and the patient's values and preferences.

Our study, "Improving Methods of Incorporating Racial/Ethnic Minority Patients' Treatment Preferences Into Clinical Care" used a mixed-methods approach to study the presence of experiences of discrimination in healthcare settings and how exposure to discrimination may impact quality of healthcare as well as preferences for treatment for depression or diabetes.

The results from this study suggest that several SHARE domains may require modification or enhancement in order to improve establishment of trust between patients and providers, and to improve preferences elicitation in order to improve shared decision making to establish treatment plans. These suggested additional considerations may be particularly helpful for patients from a racial/ethnic minority background, who are more likely to experience discrimination, and those who have experienced discrimination for other reasons (e.g., because of a mental health diagnoses or perceived socioeconomic status).

Citations:

Agency for Healthcare Quality and Research. "The SHARE Approach: A Model for Shared Decision Making." AHRQ Pub. No. 14-0034-1-EF (2016) Rockville, MD, USA.

Agency for Healthcare Quality and Research. "The SHARE Approach. Essential Steps of Shared Decision Making: Quick Reference Guide (Workshop Curriculum: Tool 1)." (2014) Rockville, MD, USA.

Prior to beginning SHARE approach

<p>Current Recommendation</p>	<p>According to the SHARE Approach, “The shared decision making process begins when your patient has a health problem that needs a treatment decision.”</p>
<p>Suggested Guideline Enhancements</p>	<p><u>Before</u> embarking on SHARE is a time to start building trust with the patient, which may be especially critical to enabling shared decision making in those who have experienced discrimination.</p> <p>Providers should consider also:</p> <ul style="list-style-type: none"> ● Finding clear ways to communicate to patients that: <i>“We care about you, we want you to be here, we will take care of you regardless of any characteristic you may have (race, class, mental health status, etc.)”</i> ● Language of this nature may be used by providers in the clinical encounter and may be valuable to include in published information about the clinical service (e.g. brochures, website) even before the first visit. ● Asking patients about past experiences (including experiences of mistreatment in healthcare settings) to help improve patient-provider alliance before embarking on shared decision making regarding the treatment plan. <ul style="list-style-type: none"> ○ Information could create changes in social interaction between provider and patient: <i>“This information will help me to understand past experiences in order to be sensitive and it would also help me to understand how I play a role in those experiences.”</i> ○ Eliciting this information may need to be supported by system-wide approaches (e.g., waiting room surveys) and supports for how providers may respond to patients who have experienced past discrimination.

SHARE Step 1: SEEK your patient's participation

Current Recommendation	<p>Communicate that a choice exists and invite your patient to be involved in decisions. Patients have a right to understand their treatment options. They may choose not to participate, but try to engage them in their health care decisions whenever possible.</p>
Suggested Guideline Enhancements	<p>Providers should consider also:</p> <ul style="list-style-type: none"> ● Communicating clearly when and why they are starting this conversation on preferences, and developing a shared understanding about how the patient has made decisions in the past and how the patient would prefer to make decisions together. It is important to understand the patient's familiarity and comfort with the shared decision making principles and process. ● Communicating that, <i>"We want to understand your preferences, fears, concerns about how you will be treated so that we can address them and so you get the care you want and need. We will put your needs first (and not our needs or financial concerns). We want to know if your needs are not being met and finally, we will be there for you, whatever happens. That is our job."</i> ● Communicating that it is a top priority that patients feel comfortable being honest with the provider about their concerns regarding treatment and any barriers to treatment, because it is the provider's job to make sure the patient's needs are being met. ● Emphasizing that the provider will not be offended by any questions or concerns the patients may have in the course of shared decision making.

SHARE Step 2: HELP your patient explore & compare treatment options

<p>Current Recommendation</p>	<p>Discuss the benefits and harms of each option. Many health care decisions have multiple treatment options, including the option of no care. Often no single option is clearly superior. Use evidence-based decision making resources to compare the treatment options</p>
<p>Suggested Guideline Enhancements</p>	<p>Providers may consider also:</p> <ul style="list-style-type: none"> ● Starting the conversation about laying out initial treatment options by further eliciting from patients questions like: <ul style="list-style-type: none"> ○ <i>“How do you understand what you are experiencing?”</i> ○ <i>“What are the biggest problems that you have faced with this issue (e.g., depression / diabetes)?”</i> ○ <i>“What are your goals for improving what you are experiencing?”</i> ○ <i>“What do you know about what might help you improve your (diabetes/depression)? What have you tried before?”</i> ○ <i>“What do you worry about getting treatment for this? And if we don’t start any specific treatment for this?”</i> ● In that context, laying out and defining treatment options; discussing and explaining pros and cons and how each treatment option may help toward the patient’s goals and may balance with worries about getting treatment vs. not getting treatment. ● Asking whether there are other opinions or information that the patient needs to understand the treatment options and pros/cons, and so they can start to think about what they want from care. Examples: <ul style="list-style-type: none"> ○ Consulting family members, other providers, or other types of providers ○ Consulting other online resources such as AHRQ decision-support tools like: https://effectivehealthcare.ahrq.gov/sites/default/files/pdf/major-depressive-disorder_consumer.pdf ○ Consulting people with lived experience with these conditions, or medications/treatments - this may be a place to incorporate Certified Peer Specialists early in someone’s treatment planning (would need to have this resource available) ● Asking about what has made obtaining and staying in medical treatment difficult (barriers) related to social determinants or other factors, and if patients have any such concerns when it comes to the aforementioned treatment options for depression/diabetes. ● Acknowledging that there are some barriers that can not be immediately addressed, but that there are places to refer to for some of these. <ul style="list-style-type: none"> ○ This may fit within the context of screening for social determinants that is increasingly occurring in clinical settings ● Follow up on initial exploration with additional ways that patients can weigh and consider what they prefer (see Step 3).

SHARE Step 3: ASSESS your patient's values and preferences

Current Recommendation	Take into account what matters most to your patient. An optimal decision is one that takes into account patient values and treatment goals.
Suggested Guideline Enhancements	<p>Providers should consider also:</p> <ul style="list-style-type: none"> ● Consider a decision support tool that uses elements of the discrete choice experiment: this would help patients weigh important treatment factors in deciding their treatment preferences for depression or diabetes. Such a tool can facilitate the treatment plan beyond the existing consumer-facing consumer decision-support tools provided in most contexts <ul style="list-style-type: none"> ○ For example, the AHRQ guide “Comparing Talk Therapy and Other Depression Treatment with Antidepressant Medicines” does not offer patients a structured way to consider factors like cost, frequency of treatment, side effects, etc. and then triangulate these considerations in a concise way. Read the AHRQ guide here. ● As with the providers’ introduction to shared decision making above, the patient-facing tool should have language on it that clearly states why it is being used: <ul style="list-style-type: none"> ○ e.g., <i>“We are collecting this information because research shows that your treatment is more likely to help you reach your goals if it is aligned with your preferences and it is something you can stick with. In research studies, we have found that people find it helpful to do this activity as a way of considering how to balance what they like about certain treatments with what they may not like or what may not be possible for them (for example, coming to see me once per week). Please think of this tool as a starting point for you to take some time to think about what matters most to you, and keep in mind that we just consider this as a starting point to have a conversation about what we should do next. We absolutely don’t have to stick with what you choose first or even what the survey says, and it will remain as protected information in your health record. We will always give you complete information about the treatment options we think are best for you. But this way we have found that we can better use our time together because you will have had some more time to think about the pros and cons, and I will have time before our next meeting to review what’s most important to you.”</i>

SHARE Step 4: REACH a decision with your patient

<p>Current Recommendation</p>	<p>Decide together on the best option and arrange for a follow-up appointment. Guide your patient to express what matters the most to him or her in deciding the best treatment option. When your patient is ready, he or she will make a decision. Your patient may also choose to delegate the decision to someone else</p>
<p>Suggested Guideline Enhancements</p>	<p>Providers should consider also:</p> <ul style="list-style-type: none"> ● Asking again, after the conversation of pros/cons as well as giving patients time to explore the treatment options using a structured decision tool, whether there are other opinions or information that the patient needs to reach a decision about treatment <ul style="list-style-type: none"> ○ Consulting family members ○ Consulting other providers or other types of providers ○ Consulting people with lived experience with these conditions, or medications/treatments <ul style="list-style-type: none"> ■ Certified Peer Specialists or community health workers may play an especially important role in helping a patient early in their treatment planning (would need to have this resource available) ● In helping patients toward reaching a decision about treatment, providers should state clearly that recommended treatment type could change over time or based on patients' experiences with treatment, that shared decision making will continue as an ongoing process throughout treatment, and emphasizing that treatments are being tailored to patient-specific circumstances and will continue to be tailored to meet patient's needs.

SHARE Step 5: EVALUATE your patient's decision

Current Recommendation	Support your patient so the treatment decision has a positive impact on health outcomes. For many decisions, particularly those related to the management of a chronic illness, decisions can and should be revisited after a trial period.
Suggested Guideline Enhancements	<p>Providers should consider also:</p> <ul style="list-style-type: none"> ● Re-emphasizing with patients that once they try the selected treatment options, the provider would like to hear from them about what is working and what is not working. ● Re-emphasizing that the provider will continue to work with them around their concerns related to what they are experiencing, and that they want to hear from the patient if they decide to stop a specific part of the treatment and why. ● Re-emphasizing that what matters most is that the patient is finding a treatment method that works for them, that they will not take it personally if an initial recommendation does not turn out to be best for the patient, and that the patient should feel like they can be completely honest about what is working and not working ● Setting specific times to check in with patients again about how things are going, for those who feel like bringing these issues up with providers is somehow “bothering” them or is not part of the routine clinical encounter.