Management of Elevated Lipoprotein (a) [Lp(a)] Levels:
Shared Decision-Making Resource for Patients and Healthcare Professionals

In shared decision-making, patients and healthcare professionals work together to make the best possible healthcare decisions. These decisions consider fact-based information about available options, the clinician's knowledge and experience, and the patient's values, questions, and preferences.

STEPS OF SHARED DECISION MAKING	SAMPLE TALKING POINTS

S — **Seek Your Patient's Participation**

What is Lp(a)?

Lp(a) stands for lipoprotein (a) and it is a type of fat and protein in your blood. Having high Lp(a) levels is a genetic condition, which means you inherited it from one or both parents. It can cause sticky build-up in blood vessels, and it increases your risk of heart disease, heart attack, stroke, and aortic stenosis (narrowing of the heart's aortic valve. While Lp(a) doesn't change much with diet or exercise, they can help you find ways to stay healthy.

H — **Help Your Patient Explore and Compare Options**

What can I do about it?

Although no medications currently exist to lower Lp(a) levels significantly, it's important to focus on reducing other risk factors if your Lp(a) is high. Eating well, staying active, and not smoking can help your overall heart health. We also can check and manage risks like high blood pressure and diabetes. You can decide which of these options feel right for you.

There are also medications that can help lower your heart disease risk. We'll work together to monitor your health and adjust the plan based on your needs and preferences.

A — **Assess Your Patient's Values and Preferences**

I'm not sure I have time to change my habits, or that I want to take medication.

High Lp(a) levels last a lifetime because they are genetic. There's no cure, but medicine and healthy habits can lower your risk of heart disease and stroke. Let's work together to find options that fit your life and support your health goals.

R — **Reach A Decision with Your Patient**

Will I need to be on treatment forever?

Am I able to continue with my daily activities?

I understand that making lifestyle changes or starting treatment can feel overwhelming. We can talk about ways to make these changes fit into your daily routine. What's most important to you as we make a plan?

E — **Evaluate Your Patient's Decision**

D — **Decide Which Resources Can Support Your Patient**

Where can I learn more?

You can learn more by talking with your healthcare team, which could include your physician, pharmacist, nurse, cardiologist, or a lipid specialist. What questions do you have?

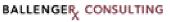**Find this resource and other guides at http://bit.ly/shared-decision.**

S Step 1: Seek Your Patient's Participation

Many patients are not aware that they can and should participate in their healthcare decision-making. Communicate that a choice exists and invite your patient to participate in the process.

"There is no one-size-fits-all approach to managing Lp(a). We'll explore what works best for you without judgment."

Summarize the health problem:

- "Lp(a) is a type of cholesterol made up of fat and protein that runs in families. This means high Lp(a) levels are inherited and can't be controlled by diet or exercise."
- "High Lp(a) can cause sticky build-up in blood vessels, raising the risk of heart disease, heart attack, and stroke."
- "You did not do anything to cause high Lp(a) levels."
- "Contributors to high Lp(a) include family history and other genetic (or familial) high cholesterol problems."
- "In women, Lp(a) levels may increase after menopause."
- "Lp(a) levels stay mostly the same throughout life, but we can take steps to lower your risk of heart problems."
- "Managing Lp(a) is just one part of heart health. Many people with high Lp(a) also have other conditions, like high blood pressure or diabetes, that need separate treatment. Together, we will create a plan to manage all your health needs".

Invite your patient to be involved in decisions. "I'd like to discuss ways to manage your Lp(a) and lower your risk for heart disease. Let's look at your options and decide together what feels right for you."

H Step 2: Help Your Patient Explore and Compare Options

Discussing options with your patient can help you build a more trusting relationship.

Assess what your patient already knows about his or her options.

- "What do you understand about managing Lp(a)?"

Explain each option clearly, using plain language. Avoid using technical or medical jargon. Point out when there are clear differences between specific options.

- "There are different ways to manage high Lp(a) and lower your risk of heart disease and stroke, including:"
  - **Medications:** "Right now, there isn't a medicine that directly lowers Lp(a), but there are ways to lower your overall heart disease risk. Some medications—like statins, PCSK9 inhibitors, and ezetimibe—can help reduce other harmful cholesterol and protect your heart. Scientists are also working on new treatments that target Lp(a) directly and may lower Lp(a) in the future. These treatments are still being studied, but we can consider new options as they become available."
  - **Lifestyle changes:** "Eating a heart-healthy diet, staying active, not smoking, and maintaining a healthy weight can help protect your heart, even though these steps don't lower Lp(a) directly."
  - "Managing other health conditions: Keeping blood pressure, diabetes, and other cholesterol levels under control can lower your overall risk."
- "Our goal is to find a couple of these things that would work or be a good fit for you. They don't all have to be done at once."
- **What about Lipoprotein Apheresis (LA)?** "Lipoprotein apheresis (LA) is a special treatment that removes extra Lp(a) and LDL cholesterol from the blood. It is only for people at very high risk who have already tried other treatments. It may not be available everywhere because it requires access to specialized centers. If you have very high Lp(a) and a history of heart problems, your doctor can help you decide if LA might be right for you."
- "More information is available at Heart.org and FamilyHeart.org."

Discuss the benefits, risks, and expected outcomes of each option. Take into account risk factors and offer evidence-based recommendations.

- "Learn about lifestyle changes, medications, and support for managing high Lp(a) and lowering your heart disease and stroke risk. Would you like help finding more information?"
  - Learn more about managing Lp(a): American Heart Association (AHA): heart.org and Family Heart Foundation: https://familyheart.org/family-sharing-tools/high-lpa-family-tools

A	**Step 3: Assess Your Patient's Values and Preferences**

Encourage your patient to talk about what is important to him or her regarding the options. Use open-ended questions and listen actively to your patient.

- "People approach health decisions in different ways. Some prefer to do everything possible to reduce risk, while others prefer to take a simpler approach. What feels like the best approach for you?"
- "Are there any challenges or concerns you have about making lifestyle changes or taking medication?"
- "What health goals feel realistic and important for you right now?"
- "What would help you stay committed to your treatment plan?"

Hear and acknowledge the values and preferences that matter to your patient. Paraphrase what you have heard. This assures your patient you are listening to his or her perspective.

- "It sounds like staying active with your family is very important to you, so let's focus on steps that support that goal."
- "I hear you that you may want to avoid medication. What are your thoughts on the options available for managing this?"

R	**Step 4: Reach a Decision With Your Patient**

Ask if he or she is ready to make a decision or if they have any additional questions. Schedule another session if your patient requests more time to consider the options or would like to engage a family member or friend to aid them in the decision-making process.

- "High Lp(a) can increase your risk of heart disease and stroke, but we can take steps to help lower that risk. Finding the right plan for you can help protect your heart and improve your overall health."
- "Now that we've talked about your options, which lifestyle changes or treatments feel like the best fit for you?"
- "Do you have any questions or concerns about the options we discussed?"
- "Is there anyone else you would like us to include to help you make this decision?"

The decisions can be documented in the accompanying **"Lp(a) Treatment Planning Worksheet" (pages 7-8 of this document)**.

E	**Step 5: Evaluate Your Patient's Decision**

Make plans to review the decision in the future. Remind your patient that decisions may be reviewed in the future, and some can be changed if they are not working well for your patient.

- "Depending on your treatment plan, we may recheck your Lp(a) along with your overall heart health to see how things are going."
- "If something isn't working for you, let's talk about it. We can adjust the plan to better fit your needs."
- "Tell me what your challenges are with taking this medication."
- "If you have any side effects from medication or if something feels too hard to manage, let me know. We can adjust your treatment or try something different."
- "Since Lp(a) runs in families, it's important to check if close relatives also have high levels. This is called cascade screening. It can help family members know their risk and take steps to protect their heart health. If you're interested, we can share resources to help you talk with your family about getting tested."
- "If you notice any new or serious health problems, please contact me or another healthcare professional right away."
- "How do you feel about this plan? Does it seem doable for you?"

D Step 6: Decide Which Local Resources Can Support Your Patient

Share resources to support patients in managing high Lp(a), including their cardiovascular care team (e.g. physician, pharmacist, nurse, cardiologist, electrophysiologist, registered dietitian nutritionist, and health plan patient navigator) and community services that can help them follow their treatment plan and maintain good heart health. Give contact information for each resource.

- "Your care team can support you in managing high Lp(a). This may include your primary care doctor, cardiologist, pharmacist, nurse, and possibly a lipid specialist or registered dietitian nutritionist."
- "Testing and resources for high Lp(a) management may be available in your community. We will make sure you have that information."
- "A registered dietitian nutritionist can help you create a heart-healthy meal plan, and a fitness professional can guide you in staying active safely."
- "If managing medications feels overwhelming, a pharmacist can help you understand your prescriptions and how to take them."
- "Would you like me to share information about local heart health programs or support groups?"
- "Have all of your questions been answered?"

References
- The SHARE Approach. Content last reviewed March 2023. Agency for Healthcare Research and Quality, Rockville, MD. https://www.ahrq.gov/health-literacy/professional-training/shared-decision/index.html
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- American College of Cardiology. An Update on Lipoprotein(a). American College of Cardiology. Published September 19, 2023. Available from: https://www.acc.org/Latest-in-Cardiology/Articles/2023/09/19/10/54/An-Update-on-Lipoprotein-a

FOR PATIENTS

To Help Manage Your Lipoprotein (a) [Lp(a)]

What are the signs and symptoms of High Lp(a)?

High Lp(a) usually doesn't cause symptoms on its own. Many people don't know they have it until they develop heart problems. It's important to talk with your healthcare professional about your risk, especially if you have a family history of heart disease.

Irregular heartbeat (at rest or when active)

Heart racing (fast or fluttering at any time)

Chest pain or pressure (sharp or dull)

Shortness of breath (difficulty breathing or tight chest)

Fatigue (consistently feeling tired)

Light-headedness (feeling dizzy or faint)

Why treat high Lp(a)?

High LP(a) increases your risk of heart disease, heart attack, and stroke. Even though LP(a) levels are inherited and don't change much over time, managing your overall heart health can help lower these risks.

Talk to your doctor about your options for managing high Lp(a). Because every person's health is different, you and your healthcare team can work together to create a plan that fits your needs. A heart-healthy lifestyle, managing other health conditions, and certain medications can all help protect your heart. Be sure to attend your medical appointments and check your lab results regularly.

Heart-healthy lifestyle
- Heart-healthy diet
- No smoking
- Little to no alcohol
- Regular, moderate-to-vigorous exercise

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Manage other conditions
- Blood pressure
- Diabetes
- Weight
- Sleep (get tested for sleep apnea)

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Cholesterol Management
- Medications to lower LDL ("bad") cholesterol and overall heart risk
- Regular blood tests to monitor cholesterol levels

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Reduce stroke risk

Medication and non-medication options

Learn more about Lp(a) at:
- Family Heart Foundation: https://familyheart.org/family-sharing-tools/high-lpa-family-tools
- Family Heart Foundation: https://familyheart.org/cholesterol-connect
- The Mended Hearts: https://mendedhearts.org/wp-content/uploads/2024/05/LPa-Discussion-Guide.pdf
  American Heart Association: https://www.heart.org/en/-/media/Files/Health-Topics/Cholesterol/What-is-Lpa.pdf?sc_lang=en

Find this resource online at https://bit.ly/shared-decision.

FOR PATIENTS AND HEALTHCARE PROFESSIONALS

Lp(a) Treatment Planning Worksheet

Visit date: _____

> What treatment goals are achievable for you?

Reason for treatment/Treatment goals

☐ Lower overall heart disease risk

☐ Reduce risk of stroke

☐ Manage high blood pressure

☐ Improve cholesterol levels

☐ Prevent future heart problems

☐ Other: _____

Treatment options

Lifestyle changes	Health condition management
Heart rhythm and rate control	**Reduce stroke risk**

Medication list

Name:	Purpose:	Dose (amount):	Frequency:
Name:	Purpose:	Dose (amount):	Frequency:
Name:	Purpose:	Dose (amount):	Frequency:
Name:	Purpose:	Dose (amount):	Frequency:
Name:	Purpose:	Dose (amount):	Frequency:
Name:	Purpose:	Dose (amount):	Frequency:

Treatment concerns (e.g. medications, costs):	Treatment plans:

Find this resource online at https://bit.ly/shared-decision.

My Cardiovascular Care Team

Primary care provider	Pharmacist
Phone:	Phone:
Email:	Email:
Nurse	Registered dietitian nutritionist
Phone:	Phone:
Email:	Email:
Other specialist (e.g., cardiologist)	Health insurance plan navigator
Phone:	Phone:
Email:	Email:
Other specialist (e.g., lipid specialist)	Caregiver
Phone:	Phone:
Email:	Email:

Screening and Lab Results

Date	Blood pressure	EKG or HR	Hgb/HCT	Total cholesterol	HDL-C	LDL-C	A1C	Creatinine

EKG/HR=electrocardiogram/heart rate; Hgb/HCT=hemoglobin/hematocrit; HDL-C= high-density lipoprotein cholesterol; LDL-C= low-density lipoprotein cholesterol; A1C = hemoglobin A1C

Additional Recommendations
- **Meet with a registered dietitian nutritionist** for personalized nutrition guidance.
- **Attend heart health education or support programs.**
- **Schedule regular follow-up appointments** to monitor cholesterol and heart health.
- **Talk with family members** about getting tested for high Lp(a), since it runs in families.