

Webinar Series



Health Literacy
Solutions Center





How to Develop Inclusive Health Decision Aids

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CommunicateHealth, Inc.

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About the Speakers

Kathleen Walker

As a Senior Content Strategist at CommunicateHealth, Kathleen creates plain language health content that educates and inspires. With 10 years of experience developing health and wellness communication campaigns, Kathleen knows how to connect with diverse consumer audiences. She excels at translating complex health information into simple and engaging content. Kathleen is passionate about creating accessible and inclusive content and promoting health literacy.

Luisa Ramirez

As a Digital Strategist at CommunicateHealth, Luisa provides strategic guidance for developing and maintaining health communication products that meet health literacy, accessibility, and user experience best practices. With a background in global health and over 5 years of experience working on digital projects, she is committed to creating innovative solutions that address users' health information needs.



Learning Objectives

1. Describe how health decision aids can support health literacy and health equity
2. Set a process for developing and testing health decision aids for a variety of audiences
3. Identify best practices in designing clear, inclusive, and accessible health decision aids that support the decisional balance of patients and their caregivers



What is a decision aid?



What is a decision aid?

- A tool that helps people think through complex health care decisions by outlining the risks and benefits of each option

Some decision aids are web-based tools, while others are printable handouts.



A good decision aid:

- Provides clear information on the benefits and downsides
- Helps people think through their values and preferences
- Includes clear next steps



What are the use cases of decision aids in health communication?

- A decision aid can help people:
 - Choose between 2 or more care options
 - Decide whether to pursue diagnostic or genetic testing
 - Decide whether to participate in a clinical trial or other research study

A decision aid **should not** replace a conversation with a doctor, but it can make those conversations more productive.



How can decision aids promote health literacy and health equity?

- Simplify the decision-making process
- Break down complex health information into easy-to-understand chunks
- Guide patients through key factors to consider
- Prompt patients to think about their personal values and what's most important to them
- Facilitate shared decision making and empower patients to have informed conversations with health care providers
- Guide conversations between patients and family members or caregivers



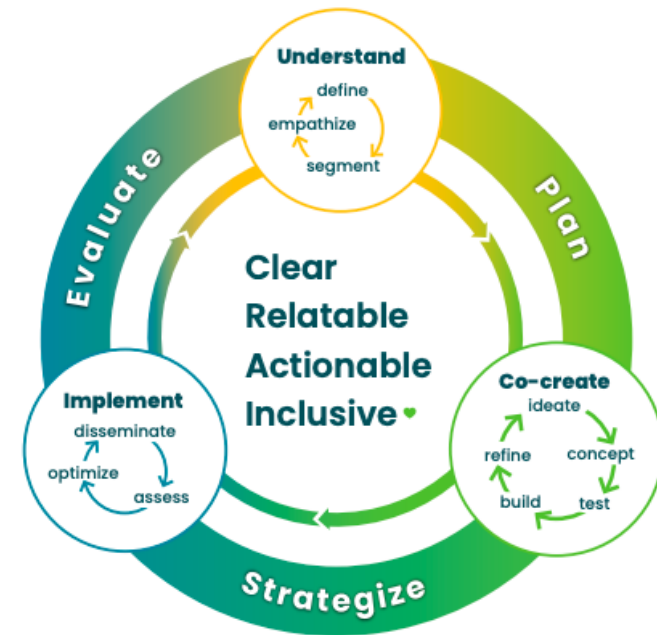
Process for developing a decision aid



Developing a decision aid

- Phase 1: Understand
- Phase 2: Co-create
- Phase 3: Implement

A Framework for Equity-Centered Health Communication



Graphic: The Equity-Centered Health Communication Process



Phase 1: Understand

- Define the health communication problem you are trying to solve
- Identify your priority audience
- Consider conducting formative research — like focus groups or in-depth interviews — with audience members



Phase 2: Co-create

- Ideate approaches and develop a prototype
- Conduct usability testing with your priority audience
- Build an accessible product
- Refine your product based on your audience's feedback



Phase 3: Implement

- Launch your product
- Evaluate
- Continue refining and optimizing



Best Practices



Best Practices: Empathetic Content

- Keep content brief
- Write in a conversational tone
- Use direct but empathetic language
- Consider including content about emotional and financial aspects of care decisions
- Talk about how each option aligns with values, beliefs and personal preferences



Downside: Emotions that may come with genetic testing

The genetic testing process may be overwhelming or confusing at times. You may feel anxious as you wait for your results. Learning about your results may bring up difficult emotions for you and your loved ones, too.





Best Practices: Clear, Interactive User Interface

- Break complex processes down into steps
- Make it personal with interactive elements like yes/no questions
- Include clear next steps



Best Practices: Inclusive Design

- Use numbers wisely
- Support your content with graphics or videos
- If using stock images, choose realistic, candid images of people who reflect your audience

Can I choose not to use a feeding tube?

The decision to use a feeding tube is yours. But it's important to understand how your ALS symptoms might change if you choose not to use a feeding tube.

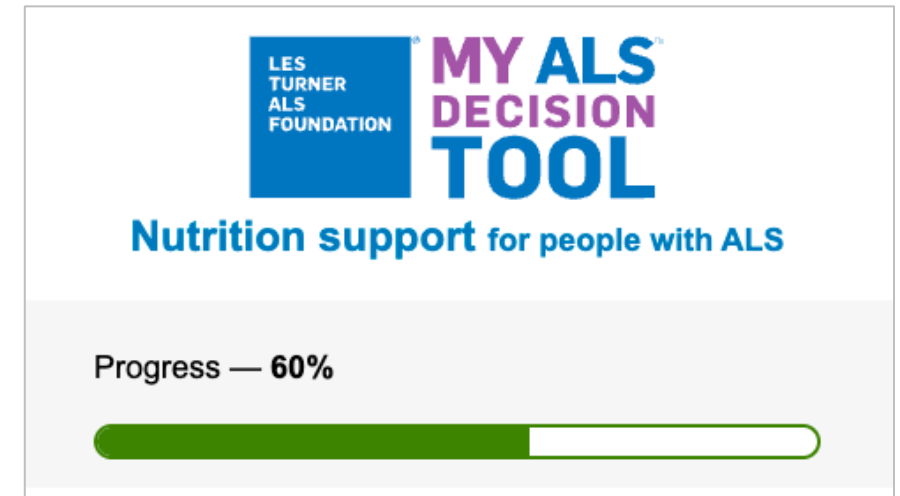
ALS is a progressive disease. This means your ALS symptoms will get worse over time. If you choose not to use a feeding tube, it may become harder for you to swallow safely, and you may be more likely to choke while eating or drinking. If you're having trouble eating, drinking, or taking medicine on your own, you may not be able to get all of the nutrition your body needs. This can lead to weight loss, infections, and other health problems down the road.





Best Practices: Progress Indicators

- Help people visualize their progress through the tool
- Include a progress bar or total number of questions





Best Practices: User Testing and Next Steps

- Test your decision aid with your priority audience
- Consider providing a printable summary of users' choices or decisions
- Provide additional resources where people can learn more



Case Studies

My ALS Decision Tool™



My ALS Decision Tool™

- CH partnered with the Les Turner ALS Foundation to create a decision support tool that helps people living with ALS make informed decisions about their care.
- The tool has 3 modules:
 - Breathing support
 - Nutrition support
 - Genetic testing

About this decision tool

Some people with ALS have trouble breathing on their own. Non-invasive ventilation, or NIV, is a special type of medical equipment that can help you breathe. Whether you're considering getting an NIV device soon or planning for your future care, this tool can help you understand your treatment options and make an informed decision.

You may benefit from using NIV if you have any of these symptoms:

- Having trouble breathing
- Feeling tired throughout the day
- Waking up during the night
- Having headaches in the morning

Even if you're not having these symptoms right now, it's never too early to plan for your future care.

You can use this tool to learn more about NIV. Then, talk to your ALS care team about NIV. Together, you and your care team can find a treatment plan that works for you.

Would you like to learn more about NIV?

[Yes, I'm ready to learn more](#)

[No, take me back to \[lesturnerals.org\]\(https://lesturnerals.org\)](#)



DONATE



My ALS Decision Tool™

- The tool explains ALS treatment and care options in plain language and guides users through complex decisions.
- Users answer a series of questions about their needs and values to help them understand potential outcomes.

Are there any disadvantages of using a feeding tube?

It's important to understand that using a feeding tube can't cure ALS or stop your ALS symptoms. And there are some disadvantages of using a feeding tube.

Select the disadvantages that are important to you.

This tool will save your answers so you can look back at them later.

☐ Select all

☐ \$ Paying for the feeding tube

Feeding tubes can be expensive, but most insurance plans help to cover the cost. Check with your insurance company to find out what your plan covers.

☒ Taking care of the feeding tube

You'll need to keep your feeding tube clean and set up your feeding bag or pump when you're ready to eat. These tasks take time, and you'll need to adjust to a new daily routine.



Summary and Next Steps

- The tool provides a summary of the user's responses and links to ALS resources to facilitate more informed conversations between people living with ALS, families, and their care teams.

Quick recap




Let's review what you've learned so far.

Some people with ALS have trouble eating, drinking, and taking medicine on their own. A feeding tube is a type of medical device that can help you get the nutrition you need.


Using a feeding tube can improve your quality of life and help you live longer with ALS. But it's important to understand that a feeding tube can't cure ALS or stop your symptoms. If you choose not to use a feeding tube, your ALS care team may recommend palliative or hospice care to help you stay comfortable and manage your symptoms.

It's important to understand the benefits and disadvantages of using a feeding tube.

You said these benefits are important to you:

-  Lowering your risk of choking when you eat, drink, or take medicine
-  Making mealtimes less stressful — for you and your loved ones
-  Maintaining your strength and keep you from losing too much weight

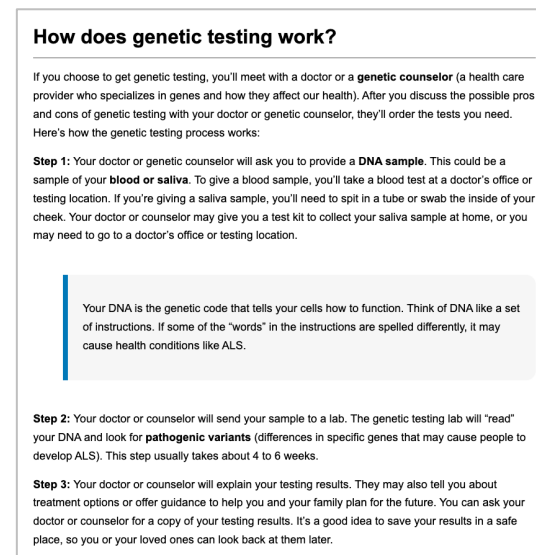
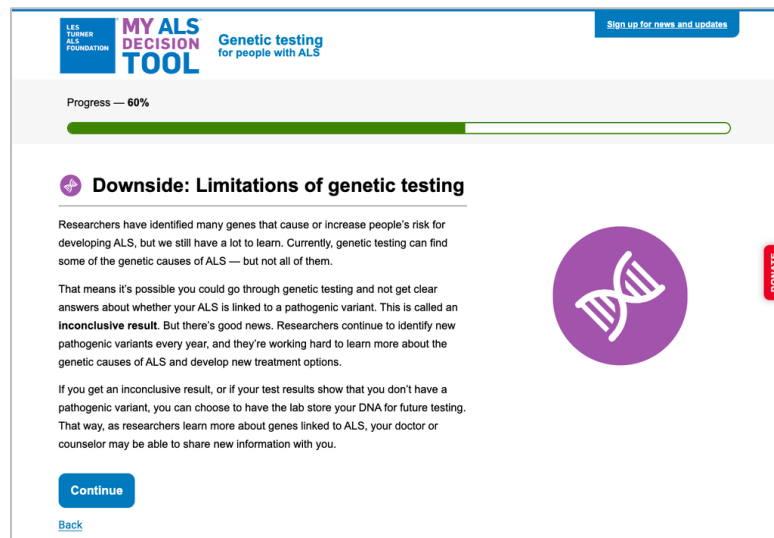
And these disadvantages are important to you:

-  Taking care of the feeding tube



Content and Tone

- The tool breaks complex information down into short chunks and accessible language.
- CH used a friendly and accessible tone while acknowledging the realities of living with a progressive disease.





User Testing for the My ALS Decision Tool™

- CH conducted usability testing with adults living with ALS and their caregivers.
- CH made several design and content updates to improve usability, like:
 - Adding spacing between buttons to improve navigation for people with mobility loss
 - Using larger fonts and buttons

You might benefit from using NIV in the near future.

You can use this tool to learn more, then talk to your ALS care team about your treatment options.

Would you like to learn more about NIV?

Yes **No**



My ALS Decision Tool™ Feedback

- People living with ALS have shared positive feedback on the tool's warm tone and approachable content.
- The tool won a ClearMark Award from the Center for Plain Language in 2022.

Some people may choose not to get genetic testing for these or other reasons. No matter what you decide, your ALS care team is here to listen and support your decision. Remember, **you get to choose**:

- Whether to have genetic testing
- What to do with the information you learn from genetic testing
- Who to share your results with



Case Studies

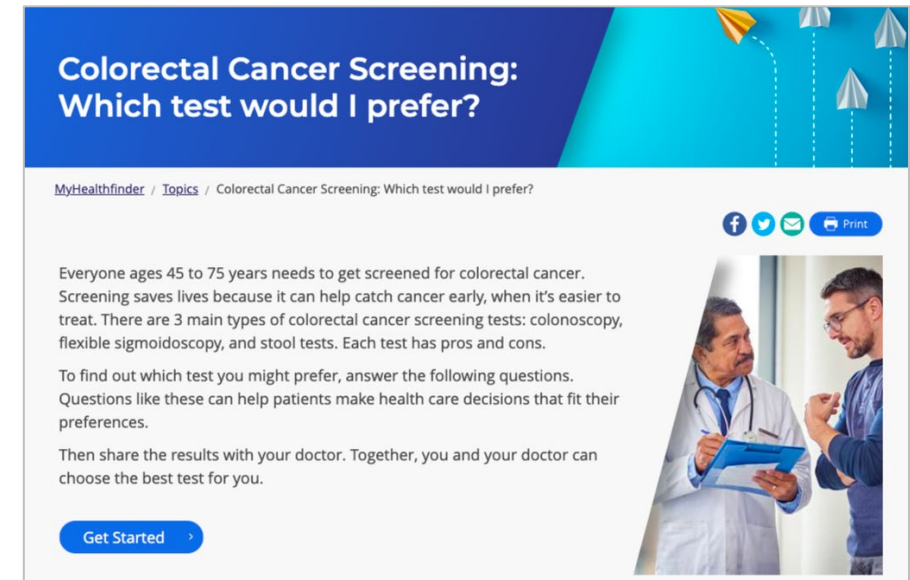
MyHealthfinder

Colorectal Cancer Screening: Which test would I prefer?

MyHealthfinder Colorectal Cancer Screening Tool



- CH partnered with the Office of Disease Prevention and Health Promotion (ODPHP) to develop a decision aid to help people choose a colorectal cancer screening test.





Colorectal Cancer Screening Questions

- The tool guides users through 7 questions to help them:
 - Learn about different types of colorectal cancer screening tests
 - Identify their values and preferences
 - Make a screening plan with their doctor

Question 2 out of 7

For a colonoscopy or flexible sigmoidoscopy, you need to go to a doctor's office or hospital. For a stool test, you do the test yourself at home in private.

How much would it bother you to have to go to a doctor's office or hospital?

- ☐ **It would bother me a lot.** I really don't want to go to a doctor's office or hospital.
- ☐ **It would bother me a little.** I'd rather not go to a doctor's office or hospital, but I can.
- ☐ **It wouldn't bother me.** I'm okay with going to a doctor's office or hospital.

< Back

Next >



Summary and Next Steps

- After users complete all the questions, the tool provides a recommended screening test, clear next steps, and additional information.

Based on your answers, the test you might prefer is a: [colonoscopy](#)

From your answers, it sounds like:

- ✓ You'd rather not drink a laxative before the test but you would.
- ✓ You're okay with going to a doctor's office or hospital to get the test.
- ✓ You can take some time off for the test, but you'd rather not take the whole day off.
- ✓ You could get someone to drive you home after the test.
- ✓ You'd rather not have any discomfort or pain during the test, but you could deal with some if you need to.
- ✓ You're okay with a test that has a small risk of serious complications if the test is very accurate.
- ✓ You really only want to get screened every 10 years.

Talk with your doctor

Use these results to start a conversation with your doctor about colorectal cancer screening. Your doctor can explain the tests further and help you decide which option is right for you.

Learn more

Want to know more about colorectal cancer screening tests? Check out the descriptions below.

- + [Colonoscopy](#)
- + [Flexible sigmoidoscopy \(flex sig\)](#)
- + [Stool test](#)

Under the Affordable Care Act, health insurance plans must cover screening for colorectal cancer. Depending on your plan, you may be able to get screened at no cost to you. Check with your insurance company to find out more.

You may also be interested in:

- [Get Tested for Colorectal Cancer](#)
- [Colorectal Cancer Screening: Questions for the doctor](#)
- [Colorectal Cancer Screening: Conversation starters](#)

[Retake Quiz](#)



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Takeaways



What questions do you have?

Please type your questions in the Q&A box.



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