



Because Health Care Isn't One Size Fits All: A Program on Personalizing Your Health Care

Facilitator Guide

Why this Program-in-a-Box?

Each of us is unique. Our health is shaped by the interaction of our genes, our lifestyle and our environment. Ideally, when we go to the doctor, we hope to receive a correct medical diagnosis and a treatment plan that meets our unique needs. This specific approach to health care is called Precision Medicine. The *All of Us* Research Program from the National Institutes of Health is a Precision Medicine program. It's working to find unique answers to medical treatment and preventive care reflective of the rich diversity of different populations here in the United States in order to advance medical care for all of us.

Starting today, we can participate in our own health and well-being by learning to advocate for ourselves during our medical visits. By engaging in these visits we receive health care that is clear to us and supports our health goals. To many, healthcare is a mystery, but it doesn't need to be. This Program-in-a-Box will help librarians share with members of their community a simple way to pursue individualized medical care tailored to their needs.

**BECAUSE
HEALTH CARE
ISN'T ONE SIZE
FITS ALL.**

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Overview

This Program-in-a-Box was developed by the National Network of Libraries of Medicine *All of Us* Community Engagement Network in cooperation with the Public Library Association. It is intended to be delivered to public library patrons by library staff.

The program consists of three parts:

1. Precision Medicine (20 minutes)

In the opening segment, you and your audience will watch a series of four short videos lasting about eight minutes total and review the definition of precision medicine. You will then engage in a brief discussion on the topic using a set of suggested questions. Feel free to adjust according to what most interests your audience.

2. Talking With Your Doctor (20 minutes)

In this segment, you will introduce the important concept of participants being an active participant in their healthcare. You'll share 3 short videos, two handouts and then conduct a brief self-reflection exercise designed to help individuals prepare for their next medical visit.

3. Craft Project: Inspiration Board (30 minutes)

In this segment, participants will create a visual project that will allow them to reflect on individual aspects of their health influenced by lifestyle, environment, and genetics. The craft project will also allow them to set health and wellness goals for the future.

For this program you will need:

- Computer or tablet device with internet connection
- Projector or other means to display video
- Handouts provided in accompanying file
- Materials for inspiration board craft activity
 - ❑ Board – Some type of large board (poster board, cardboard, large paper).
One for each participant
 - ❑ Magazines with lots of pictures
 - ❑ Other images and text from artwork, old books, computer printouts, personal photos, old postcards, etc.
 - ❑ Scissors
 - ❑ Glue
 - ❑ Colorful pens, pencils, and markers
 - ❑ Additional art materials -- yarn, feathers, buttons, construction paper, etc.

Note:

- Paragraphs marked by the word Facilitator are suggestions for what to say.
- Items marked by the 🖐️ symbol are instructions for what to do.

Have fun!

Part I – Precision Medicine

Time: 20 Minutes

Facilitator: We will start by talking about something called Precision Medicine. As you will see in the four short videos we are about to play, precision medicine is a way of going from the one-size-fits-all approach when diagnosing and treating patients to a strategy that accounts for individual differences among people. The All of Us Research Program mentioned in the videos is designed to make sure the knowledge on which this form of medicine is based represents everybody. We will talk more about precision medicine when the videos are done.

 **Play video playlist at**

<https://www.youtube.com/playlist?list=PLa1NkVjx11yb5S0MxcmsTXLH6oluPFTHo>

 **Display the slide at**

<https://drive.google.com/file/d/14ieDAOaAbHRNkGc5-Mblcwmoqq-EtLTX/view>

Facilitator: To review, precision medicine is a new approach to improving health, treating disease and finding cures. It acknowledges that each person is unique—our habits, our environments, and our biology—and that the interaction of these factors greatly impacts our health. These unique variables also mean that a medical treatment that works for one person might not work for another.

Rather than using a cookie-cutter, one-size-fits-all approach, precision medicine aims to deliver the right treatment for the right person at the right time, and keep people healthy longer. Ultimately, precision medicine can produce more accurate diagnoses, earlier detection, and better prevention strategies and treatment choices. Precision medicine is a radical shift in how each of us can receive the best care possible based on our unique makeup.

 **Start a group discussion on the videos. We suggest questions like these:**

Facilitator: Have you ever been in a health-care situation where individual differences made you an exception to the one-size-fits-all approach? Only share medical information that you are comfortable sharing.

Facilitator: Which do you focus on more when thinking about your own health and wellness decisions – your genetics, your environment or your lifestyle? Why?

Facilitator: How can you help your healthcare provider respond to your individual characteristics?

Facilitator: What are your thoughts about sharing your health information with researchers if it might improve the health of your community and family?

 **Distribute Handout A as information that participants can read later.**

Part II – Talking with Your Doctor

Time: 20 Minutes

Facilitator: It's really important for you to be an active participant in your health care in order to receive the best care and avoid misunderstandings or misinformation that can end up hurting your health. Some ways to actively participate in your healthcare are to

1. Prepare for your medical visit
2. Have an honest conversation with your doctor
3. Ask questions so that you understand what your diagnosis or condition means; how to take any medicines prescribed or prepare for other kinds of treatments your doctor recommends and also plan for any upcoming medical tests.

We will start by watching 3 short videos produced by the National Institutes of Health that cover each of these points.

 <https://www.nih.gov/institutes-nih/nih-office-director/office-communications-public-liaison/clear-communication/talking-your-doctor>

Facilitator: As you'll hear in this first video, communication is a two-way street. One way to help you communicate during your medical visit is to prepare for it ahead of time. This video shares tips for preparing for a medical visit.

 **Play Video 1: Preparing for Your Medical Appointment (4:37)**

 After the video, **Facilitator:** Would anyone like to share if you heard anything in this video that was new to you about preparing for a medical visit?

Facilitator: Our next video stresses the importance of being open and honest with your healthcare provider and how honest communication helps you get the best medical care possible.

 Play Video 2: Talking Openly with Your Medical Provider (3:51)

 After the video, **Facilitator:** If you've shared personal information that was hard to talk about with your healthcare provider, can you tell us how your doctor responded – was it a positive or negative experience?

Facilitator: Have you ever left an appointment without fully understanding your medical diagnosis, what your treatment plan actually is or what things you need to do in order to get better? If so, this video offers some tips for successfully understanding your diagnosis and being able to carry out your treatment plan.

 Play Video 3: Understanding Diagnosis and Treatment (3:57)

 After the video, **Facilitator:** What was your favorite tip or suggestion for understanding your diagnosis or treatment?

👉 **Facilitator: Thank participants** for sharing their thoughts.

Facilitator: I have two handouts to share with you that focus on “Talking with Your Doctor” that I’ll pass around the room. They both have suggested questions to ask during a medical visit and also tips for planning your next medical visit. I’ll give you just a couple of minutes to look these over.

👉 **Share Handouts B and C**

👉 **Facilitator Introduce Reflective Exercise (Handout D):** In order for the information we’ve learned here to stick in our brain, it’s important to practice. I’m going to share a handout with you that has a self-reflective exercise. Your answers on this sheet are for your eyes only and for you to take home with you. I’ll pass these out and then give you a bit of time to complete this exercise.

Part III – Inspiration Board

Time: 30 minutes

Facilitator: Inspiration boards (also called vision boards) are a great way to reflect on decisions and set goals. Inspiration boards are fun and creative ways to visualize goals, values, and intentions. Now you will each create your own inspiration board that you can use to reflect on your health decisions and set health and wellness goals.

👉 Distribute materials for participants to create their inspiration boards.

What you will need:

- Board – Some type of large board (poster board, cardboard, large paper). One for each participant
- Magazines with lots of pictures
- Other images and text from artwork, old books, computer printouts, personal photos, old postcards, etc.
- Scissors
- Glue or other adhesives
- Colorful pens, pencils, and markers
- Additional art materials - yarn, feathers, buttons, construction paper, etc. Be creative with inexpensive materials that you have on hand or can purchase.

Facilitator: You can create an inspiration board that reflects your own individual health. Think about our previous discussions on precision medicine and how environment, genetics, and lifestyle can all affect your health status. Look through magazines and materials and choose items that would best reflect what you want your inspiration to show. Cut out pictures from magazines to paste on the board, draw your own pictures or words, and decorate with additional materials.

☞ Provide examples of things participants can think of to help inspire creativity in creating their board. While they create have participants think of

- Family health conditions
- Chemicals in the environment that may affect their health and ways to avoid interaction with harmful environmental factors
- Lifestyle goals that you hope to achieve such as improved eating habits, exercising more, improved sleep habits
- These are just a few examples, participants can think of their own goals for health and wellness and the best way to visualize it on the board

☞ Allow time for participants to create their inspiration boards. If possible, create some sample inspiration boards before this program but let participants know that their inspiration boards can look however they would like.

At the end of the activity time, you can ask for a few volunteers to show the group their inspiration board and explain to the degree they feel comfortable some of the items that they have placed on the board. Also remind participants about different ways that they can use their inspiration boards:

- Participants can hang up their inspiration board in a place where they can see it on a regular basis. This will provide a daily reminder about aspects that affect health and goals for healthy living in the future.
- Participants can chose to add to their inspiration board as time goes on.
- Inspiration boards can also be viewed as a reminder of various influences on health -- lifestyle, environment, and genetics -- and actions that the individual can do toward improved health.

ADDITIONAL PROGRAMMING SUPPORT

The National Network of Libraries of Medicine (NNLM) supports Network members in their efforts to improve the public's access to health information and to enable them to make informed decisions about their health. NNLM Network membership is free. The **NNLM All of Us Community Engagement Network** (<https://nnlm.gov/all-of-us>), a partnership between the National Library of Medicine and the *All of Us* Research Program, provides support and engagement opportunities for public libraries by:

- Providing professional development opportunities, such as free training, to increase knowledge of health information resources and staff skills in providing outreach.
- Offering funding for health information projects.
- Providing tools for exhibiting at library outreach programs, health fairs and other venues
- Connecting public libraries with other Network members in their area for opportunities to collaborate.

NNLM Network Members can order free print resources for library displays and programs by contacting their **Regional Medical Library** (<https://nnlm.gov/regions>).

If your patrons enjoyed this program, consider offering **Engage for Health** (<https://nnlm.gov/mar/guides/programming-class/engageforhealth>). Engage for Health is a one-hour flexible “program-in-a-box” that provides tools libraries and organizations can use to conduct a community education program on taking an active role in your healthcare and has been proven to encourage doctor-patient communication.



Because Health Care Isn't One Size Fits All: A Program on Personalizing Your Health Care

Program Handouts

HANDOUT A

More on Precision Medicine

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More on Precision Medicine

These resources go into more depth about precision medicine and how it can impact your health care:

Genetic Science Learning Center: Precision Medicine

Collection of articles and videos covers precision medicine in depth. Originally developed by the University of Utah.

<https://learn.genetics.utah.edu/content/precision/>

Personalized Medicine: Redefining Cancer and Its Treatment

Three-part feature article explores what personalized medicine means for cancer patients. Part 1 covers the basics of personalized medicine for cancer care, Part 2 discusses where personalized cancer care stands today, and Part 3 reviews personalized medicine for cancer prevention.

<https://www.cancer.org/latest-news/personalized-medicine-redefining-cancer-and-its-treatment.html>

Genetics Home Reference Primer on Precision Medicine

National Library of Medicine resource provides the essentials on precision medicine and the federal government's Precision Medicine Initiative.

<https://ghr.nlm.nih.gov/primer/precisionmedicine/definition>

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HANDOUT B

Talking with Your Doctor: Making the Most of Your Appointment

Talking With Your Doctor

Make the Most of Your Appointment

Patients and health care providers share a very personal relationship. Doctors need to know a lot about you, your family, and your lifestyle to give you the best medical care. And you need to speak up and share your concerns and questions. Clear and honest communication between you and your physician can help you both make smart choices about your health.

Begin with some preparation. Before your health exam, make a list of any concerns and questions you have. Bring this list to your appointment, so you won't forget anything.

Do you have a new symptom? Have you noticed side effects from your medicines? Do you want to know the meaning of a certain word? Don't wait for the doctor to bring up a certain topic, because he or she may not know what's important to you. Speak up with your concerns.

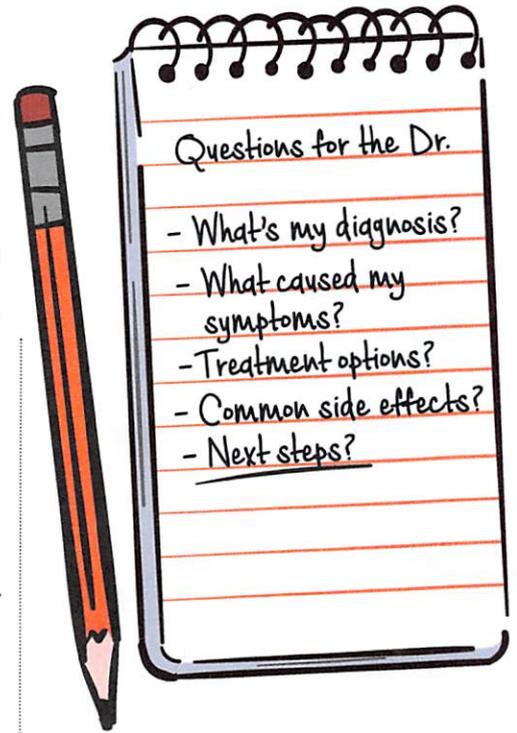
"There's no such thing as a dumb question in the doctor's office," says Dr. Matthew Memoli, an infectious disease doctor at NIH. "I try very hard to make my patients feel comfortable so that they feel comfortable asking questions, no matter how dumb they think the question is."

Even if the topic seems sensitive or embarrassing, it's best to be honest and upfront with your health care provider. You may feel uncomfortable talking about sexual problems, memory loss, or bowel issues, but these are all important to your health. It's better to be thorough and share a lot of information than to be quiet or shy about what you're thinking or feeling. Remember, your doctor is used to talking about all kinds of personal matters.

Consider taking along a family member or friend when you visit the doctor. Your companion can help if there are language or cultural differences between you and your doctor. If you feel unsure about a topic, the other person can help you describe your feelings or ask questions on your behalf. It also helps to have someone else's perspective. Your friend may think of questions or raise concerns that you hadn't considered.

Many people search online for health information. They use Web-based tools to research symptoms and learn about different illnesses. But you can't diagnose your own condition or someone else's based on a Web search.

"As a physician, I personally have no problem with people looking on the Web for information, but they should use that information not as a way to self-diagnose or make decisions, but as a way to plan their visit with the doctor," says Memoli. Ask your doctor to recommend specific websites or resources, so you know you're getting your facts from a trusted source. Federal agencies are



among the most reliable sources of online health information.

Many health care providers now use electronic health records. Ask your doctor how to access your records, so you can keep track of test results, diagnoses, treatment plans, and medicines. These records can also help you prepare for your next appointment.

After your appointment, if you're uncertain about any instructions or have other questions, call or email your health care provider. Don't wait until your next visit to make sure you understand your diagnosis, treatment plan, or anything else that might affect your health.

Your body is complicated and there's a lot to consider, so make sure you do everything you can to get the most out of your medical visits. ■



Wise Choices

Tips for Your Doctor Visit

- Write down a list of questions and concerns before your exam.
- Consider bringing a close friend or family member with you.
- Speak your mind. Tell your doctor how you feel, including things that may seem unimportant or embarrassing.
- If you don't understand something, ask questions until you do.
- Take notes about what the doctor says, or ask a friend or family member to take notes for you.
- Ask about the best way to contact the doctor (by phone, email, etc.).
- Remember that other members of your health care team, such as nurses and pharmacists, can be good sources of information.



Web Links



For more about talking with your doctor, scan this QR code for links and videos.

Or click the "Links" tab at: <http://newsinhealth.nih.gov/issue/Jun2015/Feature2>

HANDOUT C

**Talking with Your Doctor
(National Eye Institute)**

Talking with Your Doctor

Today, patients take an active role in their health care. You and your doctor will work together to achieve your best possible health. An important part of this relationship is good communication. Here are some questions to ask your doctor to get your discussion started:

About My Disease or Disorder...

- What is my diagnosis?
- What caused it?
- Can it be treated?
- How will this diagnosis affect my health now and in the future?
- Should I watch for any particular symptoms and tell you if they occur?
- Should I make any lifestyle changes?

About My Treatment...

- What is my treatment plan?
- When will the treatment start, and how long will it last?
- What are the benefits of this treatment, and how successful is it?
- What are the risks and side effects associated with this treatment?
- Are there foods, drugs, or activities I should avoid while I'm on this treatment?
- If my treatment includes taking a medicine, what should I do if I miss a dose?
- Are other treatments available?

About My Medical Tests...

- What kinds of medical tests will I have?
- What do you expect to find out?
- When will I know the results?
- Do I have to do anything special to prepare for any of these medical tests?
- Do these medical tests have any side effects or risks?
- Will I need more medical tests later?

Understanding your doctor is key to good communication.

Here are a few more tips:

- If you don't understand your doctor's responses, ask questions until you do understand.
- Take notes or ask a friend or family member to come with you and take notes for you. Or, ask permission to use the voice recorder on your smart phone to help you remember the discussion.
- Ask your doctor to write down his or her instructions to you.
- Ask your doctor for printed material about your condition.
- If you still have trouble understanding your doctor's answers, ask where you can go for more information.
- Talk to other members of your health care team, such as nurses and pharmacists. They can also be good sources of information.

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Adapted from the National Eye Institute, Talk With Your Doctor

<https://www.nei.nih.gov/health/talktodoc>

HANDOUT D

Exercise: Talking with My Doctor or Provider

Talking with My Doctor or Healthcare Provider

It's important to your health and self-care to have an honest talk with your doctor. To support your health, be prepared for your medical visit by listing questions you want to ask.

When thinking about my next medical visit, I plan to ask the following questions:

1.

2.

3.

HANDOUT E
Patron Resource Guide

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Resource Guide

Improved health literacy and trusted health information allows you to learn more about your own health status and medical care. Use these resources to discover and learn more about unique qualities that affect individual health.

[All of Us Research Program \(https://allofus.nih.gov/\)](https://allofus.nih.gov/)

The All of Us Research Program aims to build one of the largest, most diverse datasets of its kind for health research, with one million or more volunteers nationwide who will sign up to share their information over time.

[Genetics Home Reference \(https://ghr.nlm.nih.gov/\)](https://ghr.nlm.nih.gov/)

Genetics Home Reference contains information about genetic conditions and the genes or chromosomes associated with those conditions. It also provides introductory information on precision medicine and educational resources.

[MedlinePlus \(https://medlineplus.gov/\)](https://medlineplus.gov/)

MedlinePlus is a great resource for extensive health information and features hundreds of health topics, easy-to-read materials, interactive tutorials, news, and more.

[MedlinePlus Talking with Your Doctor \(https://medlineplus.gov/talkingwithyourdoctor.html\)](https://medlineplus.gov/talkingwithyourdoctor.html)

A health topic page of the MedlinePlus website that provides various tools and information to help you get the most of your next visit to a healthcare provider.

[NIH MedlinePlus Straight Talk for Good Health \(https://medlineplus.gov/magazine/issues/spring13/articles/spring13pg26-27.html\)](https://medlineplus.gov/magazine/issues/spring13/articles/spring13pg26-27.html)

This archived article from MedlinePlus Magazine provides guidance and a list of questions that individuals can use to better prepare and communicate during their next healthcare visit.

[Tox Town \(https://toxtown.nlm.nih.gov/\)](https://toxtown.nlm.nih.gov/)

Tox Town provides information on environmental factors and how the places we live, work, and play influences our health.

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