A Guide to Family Health History

INSTITUTE FOR CULTURAL PARTNERSHIPS
## Contents

This toolkit will help you collect, organize, and understand your family health history. In Book 1: *A Guide to Family Health History*, each section includes choices of activities. Choose the activity that works best for you.

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Read Book 2: *A Guide to Understanding Genetics and Health* to learn more about:

1. Why is Genetics important to my family and me?
2. Diseases that may “run in the family”
What is family health history?

Family health history is a collection of information about diseases that “run in your family,” as well as the eating habits, activities, and environment that your family shares. Knowing about diseases in your family can help you make healthy choices.

Your family’s health is one part of the entire history of your family. While collecting your Family Health History, pay attention to events, stories, and experiences as well. Gathering your family history helps you share your heritage and culture with your relatives and future generations.

“We have a tendency to carry on family history verbally and we need to put it down somewhere. In the doctor’s office it is hard to remember all of that history that’s in your head.”
You inherit many things from your parents and grandparents. They pass on culture and values through photos, recipes, stories, spiritual practices, and music. You also inherit how you look — for example, your height and the color of your eyes. Small structures in cells called genes carry information for these characteristics and how your body works. Your genes were passed on to you from your parents.

How can Family Health History affect my health?

Carlos’ Story

Every man in my family has dropped dead before the age of fifty...my father, my grandfather, and my uncles. I always assumed that I wouldn’t make it to fifty.

A few years ago my cousin told me that he told his doctor about our family health history. His doctor did some tests and found out that my cousin was at risk for heart disease. Maybe even a heart attack.
Some genes can increase your chance of developing certain diseases. When members of your family share health problems, you might be at risk for developing the same health problems in the future. This is because family members can share genes, lifestyle, and environment in common. However, you may be able to **prevent illness by being aware of your family health history** and by making healthy choices.

He put my cousin on medication to lower his cholesterol and told him to stop eating so many fried foods.

I talked to my doctor and got the same tests and advice. Last year, I threw the biggest fiftieth birthday party ever!
How can my choices affect my health?

Many things shape your health. Some things — such as your genes — are outside of your control. Other things — such as what you eat, whether you smoke, whether you exercise, and what you do for a living — can be influenced by the choices you make. To make healthy choices, you need to understand your current health, your risk for developing certain diseases, and your environment.

Vanessa’s Story

I told a friend of mine about the family health history information that I was gathering and she said: “If it happened in my family, it is going to happen to me. Why get into it — it is going to happen anyway.” That kind
“Knowledge is power. Finding out the illnesses that run in our families can be just the motivation we need to start making healthier choices and save lives. It is never too late to care about your health.”

– Barbara E. Jackson, RN
President/Founder
Central Pennsylvania Coalition
United to Fight Cancer
“CATALYST”

of thinking can keep you from doing the little things that can help. My mother, aunt and sister all have diabetes, but I do not. I walk a little bit everyday — even if it is just a block or so. I bake my food instead of frying. Those things might make all the difference.
What information should I collect?

Collect information about:
- Yourself
- Your parents
- Your brothers and sisters
- Your children

Then move on to your extended family

Basic information to collect
- Name and relationship to you (myself, parent, child, etc.)
- Ethnicity, race, and/or origins of family
- Date of birth (or your best guess – for example “1940s”)
- Place of birth
- If deceased, age and cause of death

Collect stories about your heritage and culture. This is an excellent opportunity to preserve your family’s memories.

You don’t have to collect everything!
Who to collect info from

Collect the medical and health information on:
- Yourself
- Your brothers and sisters
- Your children
- Your parents
- Then go back a generation at a time and include:
  - Grandparents
  - Aunts and Uncles
  - Cousins
  - Nieces and nephews

Basic info to collect
- Name and relationship to you (myself, parent, child, etc.)
- Race, ethnicity and/or origins of family
- Date of birth (or if the information is unavailable, write your best guess—for example “1940’s”)
- Place of birth
- If deceased, age and cause of death

It is important to learn what you can.

- Deafness/hearing loss at a young age
- Mental Health Disorders (examples: depression, schizophrenia, learning disorders)
- Childbirth (number of children, miscarriages, complications)
- Immunizations
- History of surgeries
- Current and past medications

Health History:
Major diseases or health conditions:
- High Blood Pressure
- High Cholesterol
- Heart Disease
- Stroke
- Diabetes/Sugar disease
- Obesity
- Sickle Cell Anemia
- Cancer (examples: breast, ovarian, colon, prostate)
- Asthma and allergies
- Alzheimer’s disease
- Addiction (examples: alcohol, drugs)
- Blindness/vision loss
- Birth defects (examples: cleft lip, heart defects, spina bifida)

Lifestyle:
- Occupation
- Nutrition and diet (please note if they are very obese)
- Exercise
- Hobbies and activities
- Habits (examples: smoking, drinking, regular doctor/dentist check-up)

Be sure to record age at onset of symptoms (when the disease started)
How do I collect Family Health History?

Talk to your family

Your relatives are the best source of information about your family. Family history is often shared during conversations at family events, like birthday parties, weddings, family reunions, religious gatherings, holiday dinners, and funerals. These events provide an opportunity to ask family members about their lives.
Use what you have
Check first to see if your family has existing family trees, charts, or listings of family members. This information may be recorded in baby books, photo albums, birthday date books, or a family Bible or other religious record. Review your own medical history with your doctor to make sure that you’re not forgetting anything.

Plan an individual conversation
After you’ve introduced the idea of family health history, you may want to talk with certain family members to get a more complete record of what they know. If possible, it is a good idea to record these interviews so that you can go back later and review them. This guide includes sample questions to ask.
Tips for collecting family health history

• Start with your parents if they are still living. They may refer you to the “family historian.” Often, older relatives are good sources of information.

• If you are adopted, you may be able to learn some of your family history through your adoptive parents. You may also ask to see the adoption agency records.

• It is important to respect others. Some relatives may not want to share their medical histories. Some may not know their family history.

Lisa’s Story

Last week was my family’s twentieth annual family reunion. We’ve been having them ever since my grandfather passed away from a heart attack. We always get together and share stories, eat great food from our family cookbook, and talk about what has happened in our lives. This year I thought we should also talk about the health stories of our family.

I was a little nervous because I knew that the older generation did not discuss their health — especially cancer. They hid it like it was something bad or shameful.

Once I started the conversation, I was surprised at how willing people were to talk. All along I thought that heart disease was the biggest
• It can be alarming to find out about a health concern in your family. **Sharing family history with your health care provider can help you understand if you are at risk.**

• Family members may not clearly identify all diseases. Ask questions that invite family members to describe behaviors that might suggest health issues. For example, someone who suffered from “the blues” may have had depression.

It was a little bit scary to find that cancer runs in my family, but my doctor explained that it is better to know, because now we can do something about it. He is helping me to change my diet and exercise to reduce my risk, and he has referred me to a genetic counselor so that we can find out what else we can do. At the next reunion, we are going to share what we have learned so that everyone can benefit. Like my sister says — it’s better to know!
How do I ask my family members questions about family history?

On the next page is a list of sample questions that will help you to talk with your family members. These questions will help you learn about your family stories as well as health patterns and any impact environment, lifestyle, and family history may have on family health. Be sure to add your own questions that relate more specifically to your family.

Prepare ahead of time:
- Write down what you already know—such as relatives' names, where they were born, or how many children they have.
- Pick the questions you will ask beforehand.
- Try to record the interviews on a tape recorder or video camera.

Natasha’s Story

Since I am adopted, I thought there was no way for me to put together a family health history. Even though my adopted family and the adoption agency tried to help, they didn’t have the answers about my birth family’s health I needed. How can I have a family health history without having my questions answered?
During the conversation:
- Write down health related information provided by your relative.
- Try to keep the questions short and avoid questions that can be answered with a simple “yes” or “no.”
- Use follow-up questions such as “why,” “how,” and “give me an example.”
- Don’t expect people to know the answers to all of your questions.
- Be sensitive to a person's desire not to talk about certain topics.
- Consider asking your relative to show you photographs, recipes, personal letters, and other family memorabilia. These help people remember more details and can lead to more family stories.

Try not to interrupt—let your family member tell his or her story!

There is something I can do. I am starting my family health history with me and my health issues—like the fact that I started wearing glasses when I was 12 years old. I will pass on the information to my children and they will be able to add on to our family history.
Sample Questions

Questions about childhood:
- Where were you born?
- Where did you grow up?
- Did you experience any health conditions (for example allergies) as a child?
- Do you have any brothers or sisters? Did any of them pass away during childhood?
- What did you do for fun as a child?

Questions about adulthood:
- What jobs have you had? Can you tell me about a typical day?
- What was your work environment like?
- Do you have children? What are their names and when were they born?
- What habits have you had that could have affected your health (sun exposure, physical activity, smoking)?
- Did you develop any health conditions or illnesses as an adult? At what age? Did any of these conditions require medical treatment or surgery?
- What is the most important thing you do today to keep yourself healthy?
Questions about parents and grandparents

• When and where were your parents born? What do you know about them, for example their occupations and pastimes?
• What do you remember about your grandparents? Where and when were they born?
• Do you recall any health conditions or physical ailments that affected your parents and/or your grandparents?
• Do you recall if they took any over the counter or prescription medications on a regular basis? If so, what for? Did they use home remedies? What kinds and what for?

Questions about family life:

• Has your family lived near any sites that may have been hazardous or lived through any major disasters that may have affected their health?
• What foods does your family usually eat? Describe a typical family breakfast or dinner. Were there special foods you ate for special occasions?
• Do you know of members of the family that experienced difficulties in pregnancy or childbirth? What kinds of difficulties?
• Are there any conditions or illnesses that you think might run in our family?
• Is there anything else you would like to tell me about your life or about health concerns in our family?
• Do you have a favorite memory of your family that you would like to share?
How can I organize my family health history?

The family health history information you collect can be written down or typed into the computer. It is important to summarize all of the information so that it makes sense to you, your family, and your health care provider. We have included some useful and creative ideas below for organizing your information.

Family Health Portrait

A Family Health Portrait is a special version of a family tree showing relatives and their health. Because it is a simple picture of your family health history, it can be easily shared with your health care provider. Turn to page 18 for more information.

Isabel’s Story

My grandmother died of a massive heart attack when she was 39 years old. Even though my mother was so careful about health care for our family, she did not know that she herself had a very serious heart condition. She felt just fine, but during a routine checkup two years ago, a doctor discovered my mother’s uncontrollable heart arrhythmia. Mom was taken to the hospital immediately and a cardiac pacemaker was implanted the following day. Since they knew that my grandmother had died of a heart attack at a young age, they took my mother’s symptoms very seriously.

This knowledge about my mother and grandmother’s health does scare me but I feel that it is good to know. I know you can feel healthy but
a guide to family health history

I have a serious health condition. Whenever I go for my check-ups I always talk to my doctor about my grandmother and mother’s heart conditions. She checks my heart thoroughly and always runs a special test on it because of my family health history.

Though I can’t change what happened to my mom and grandmother, I can use the information to better manage my health and lower my risk.

Healthcare Provider Card

In your Does It Run In the Family toolkit, you will find a card to fill out and bring your provider. The card focuses on concerns you have about your family health history. It also gives your provider more information on how to best use your family health history to determine your risk for getting a disease.
How can I draw a Family Health Portrait?

If you have access to the Internet, you can use the US Surgeon General’s My Family Health Portrait to create a family health history tree on your computer. https://familyhistory.hhs.gov/

You can also draw your own Family Health Portrait. Use the example on the next page to help guide you.

Instructions for drawing a Family Health Portrait

• Write your name and the date at the top of a large piece of paper

• Draw yourself at the center using a square if you are a man or a circle if you are a woman

• Draw your parents above you and label each symbol with their name and birth date (or approximate age)

• Draw a line between them and then draw a line down to you

• When possible, draw your brothers and sisters and your parent’s brothers and sisters starting with the oldest to the youngest, going from left to right across the paper

• Add the health information you collected for each individual

• Add the country of origin and any other information you have collected

Family Health Portrait Legend

☐ male  ◯ female  ☑ deceased
Kim’s story

1. To start my family health portrait I added myself. Any women on the portrait are drawn with a circle. Under my name I wrote my birth date.

2. Next I drew in my mother and father. I connected them to each other using one line and drew another line that connected to me.

3. Next I added my brother and sister and also put in their birthdates. I connected each of them to the line that connects my parents. Any men in the portrait are drawn as squares.

4. For my father’s parents, I put their names above his and drew one line connecting them to each other and another connected to me. I also added that they were from Mexico and that my grandmother died of a heart attack at 42.
What Now?

• Save and update with new information you learn about your family

• Find out more about diseases that run in your family and learn how to stay healthy

• Share information with your family

• Take a clear summary of your health history to your health provider

• Read the next booklet, “Does It Run In the Family: A Guide for Understanding Genetics and Health.”
Resources

Genetic Alliance Family Health History Resources
http://geneticalliance.org/familyhealthhistory

Institute for Cultural Partnerships
http://www.culturalpartnerships.org

A Guide to Interviewing - Smithsonian Institution
http://familyoralhistory.us/news/view/the_smithsonian_folklife_and_oral_history_interviewing_guide/
and visit the American Folklife Center website,
http://www.loc.gov/folklife/fieldwork/index.html
The Institute for Cultural Partnerships is a private, non-profit organization whose mission is to facilitate opportunities for understanding among diverse cultures and communities.