

Family Health History

Focus Groups

Dayton, OH
Cincinnati, OH

December 5-8, 2006

Table of Contents

INTRODUCTION	3
Study Objectives	3
Methodology	3
Demographics	3
DETAILED FINDINGS	4
Family	4
Family Health History	5
The Program	11
Surgeon General's Family History Initiative – paper tool	13
Surgeon General's Website – <i>www.familyhistory.hhs.gov</i>	17
Informational Printouts	19

INTRODUCTION

Study Objectives

The ultimate goal of this project is to develop a program consistent with the US Surgeon General's Family Health Initiative to encourage US citizens to be aware of and record their family's health history.

The target audience of this program will be persons of Appalachian descent with less than a college degree.

The goals of this research are to:

- Understand family dynamics – who holds all of the information about family health?
- Understand the importance of knowing family health history
- Ascertain which tools will be effective teaching aids to use for the program

Methodology

Two (2) focus groups were conducted. One on December 5, 2006 in Dayton, OH and another on December 8, 2006 in Cincinnati, OH. Each group lasted approximately 2 hours and was audio and video taped.

Both groups were recruited by volunteers at local community centers.

Demographics

Twelve female participants of known Appalachian descent were recruited in each city.

Education Level:	Dayton	Cincinnati
No HS diploma	1	4
GED	0	5
HS diploma	3	2
Some college*	5	1
College degree	2	0
Age:		
20-29	2	5
30-39	3	3
40-49	2	2
50-59	4	2
Over 60	1	0
Race:		
White	7	9**
Black	2	2
White/Cherokee	2	1
Other (not specified)	1	0
Number Of Children		
0	4	1
1-3	5	7
4+	3	4

* Includes those in a certificate or associate program

** Includes five who self-identified as "Appalachian/White"

The number in brackets following each verbatim refers to the specific focus group:

[1] Dayton, OH

[2] Cincinnati, OH

DETAILED FINDINGS

Family

Defining family

All participants recognize that there is a difference between the people who they select to be in their family and their “blood” relatives. There are people who are considered family because of similar interests, long-term friendships and a bonding that takes place through love and caring. These are people who become close to the individual; they are best friends and companions that are considered family.

“Blood” relatives are the people in the family who are related by blood. These are the people that are born into the family and have a common ancestry. They may or may not be the people an individual loves and cares about the most.

“There are the people that you love and care about the most. The ones you can turn to are your family.” [2]

“The people you love.” [1]

“A bond, a strong link.” [1]

“My immediate family are my best friend, her kids and all my other friends.” [1]

“I think people just come together and it just feels like family after a while.” [1]

“You can talk to someone and realize that you’ve known them for 20 years, they just become family.” [1]

“Father, mother, it could be blood or not. You can have a real close friend that you have had for years.” [2]

“I have a friend for 30 years and I love her dearly and she is just part of the family. Family is blood and not blood.” [2]

“You can’t get rid of the ones that are blood.” [1]

“I am not close to a lot of my blood relatives but whenever they need something they call me and say that we are blood. What does that mean, I do not know?” [1]

“It means a certain amount of loyalty.” [1]

“You have a blood family and a choice family. The blood family you may not want to be around because you did not choose to have them, then it is your choice family and those are the people who want to be around.” [1]

Family size

With only a few exceptions, most of the participants have huge “blood” families. They report grandparents and parents having 10 to 20 children. Interestingly, the majority of this generation of Appalachians is having fewer numbers of children. Most reported only having 2 to 4 children of their own.

“My parents are deceased and I am from a family of 21 kids and there are only 3 left. Our close family, although we do not see one another often because we are spread all over the world, we still stay in close contact. Get on the computer and send e-mails. We contact one another once or twice a year. We have done the genealogy clear through my mother and father’s side of the family. What we came up with is heart problems and strokes run on both sides of the family. Most of them have heart problems. I had an 11 year old cousin that fell dead from a heart attack. My sister and my brother got together on the computer and started hunting down relatives.” [1]

“I personally do not know my family tree, my family is so big that I do not know everyone.” [2]

“That is how I am too, my family is so big. We had a family reunion at Cooney Island and we filled up the place and everybody there was related to me. I think it was all blood family.” [2]

“My great grandmother had 15 children, my grandmother had 10 children. The fewest children was 5.” [2]

“My grandmother had 21 children.” [2]

“My mom had 11 children.” [2]

“My mom has 7 sisters. My husband has 7 brothers and there are 14 different aunts and uncles and those are only the ones I know.” [2]

“My grandmother had 13 children, my mother had 6, and I have 4.” [2]

“My mom’s side there are not too many, maybe 8. She had 8 but only 5 survived. But on my husbands side his grandma has 18 and his mom had 10.” [2]

Family Health History

Define Family Health History

The majority of participants appeared to be familiar with the term Family Health History (FHH) and correctly define it as the health or the illnesses that reoccur in the family blood line – knowing what diseases are passed down from one generation to the next. Many comment that whenever they go to a doctor they are always asked about their family and what illnesses or diseases run in their family.

- Relatives that are important to consider in the FHH are parents and grandparents, siblings, aunts and uncles.
- Illnesses that are believed to be hereditary are hypertension, diabetes, heart disease, cancer, depression, mental illnesses, stroke, asthma, high cholesterol and obesity.

“It means grandparents, father, mother, the whole blood line.” [1]

“The doctor always asks you that, what your family history is.” [1]

"Illnesses that reoccur in your family line. Like hypertension, diabetes, heart trouble." [1]

"If they are not blood then your health is not mixed in with them." [2]

"Usually they specify mother, father, brothers and sisters. I think it should go way back." [1]

"Mothers, fathers, grandparents. Uncles, sisters, brothers." [2]

"Nieces and nephews if there was something that stood out." [2]

"Cancer, heart disease, diabetes, depression, stroke, thyroid, emphysema, asthma, cholesterol, Diabetes, cancer, HBP, cholesterol, obesity"

The terms hereditary and genetics are familiar to participants. They understand that these are family traits that are passed down through the blood line from one generation to the next.

"It is passed down through the family – the blood family." [1]

"Genetics is the same thing." [1]

Who knows the FHH in your family?

The keeper of the knowledge of the FHH appears to be an elder dominant female in the family; either the oldest surviving female or the one with the most dominant personality. The information may or may not be passed down to her daughter or daughter-in-law or a niece. Information may be passed down orally or in written form. In general, it appears that if a younger member of the family has a question about the FHH they will naturally ask their mother or grandmother. If these persons are deceased than they will go to an aunt or other female member who they believe knows the information.

In some families there are self-appointed keepers of the family history. There are women who have graphed the family tree, along with some major illnesses. They have researched genealogy and relationships to portray the parentage of all "blood" relatives in the family.

"I do. Both of my parents are gone and both sets of grandparents are gone. So whenever anything comes up in the family I am the one that gets the phone call now. I was always the one who really cared; we investigated and started the genealogy. My mom was the only person in her family that stayed in one place for a period of time so everyone always called her and now the information has funneled to me. My aunts and uncles have moved around constantly so I am now the family historian." [1]

"It is from my Aunt Linda. She pulls up the family trees and everything else. She likes to talk and she calls you to inform you about what is going on whether you want it or not. If I needed to know anything I would ask Aunt Linda. When she dies it will probably be my mother, her sister. My mom and Aunt Linda just talk. My grandpa died of tumors in his head and ever since then she has been a fanatic and has to know everything about everybody. She even had my uncles get tested for different stuff. She is building a book for every one of us." [1]

"My step-father adopted me and I did not find out until much later who I belonged to so that has made it tough. My mother never had any brothers and sisters so I kept track of my great aunts and uncles so I kept track of that. My children have had various fathers. Now I have a computer and I have followed the genealogy, I am the keeper now. If they need anything they e-mail me. I have all the pictures and when people were born and died and illnesses they had. On my father's side my grandmother lived to be 104. Most of his brothers and sisters lived to be 90. None of my brothers or sisters has any illnesses." [1]

"I do not know, my parents are both dead and my sister and I are close. I had an aunt who passed away last year in an accident. She was on my dad's side of the family and she was the one I could call and ask about things. I talk to her husband sometimes and I have another aunt on my dad's side. My mom's side of the family, they are all passed away. No one kept track on my mom's side. She had brother's and sisters that were cousins because my grandpa married family. I do not know about my mom's side. My dad's side I have an uncle that has kept track of things but I do not talk to him too much." [1]

"My grandmother used to do it but my mother took over since my grandma passed away. If someone needs to know something, my mom keeps a big list in a file cabinet, the whole history." [2]

"We have a big tree, it is so big. But my grandmother keeps up with it. She writes down everybody that is born. We have a lot of Cherokee Indian in my family and diabetes is big in my family."

"I would talk to my mom. I know some of the things, my grandfather passed from cancer and I know diabetes runs in the family and my grandma has arthritis but she died of diabetes. I know some of the things I need to watch and be careful about." [2]

"I would go to my mom. My grandmother and grandfather passed when I was 7." [2]

Importance of knowing FHH

All participants realize that it is important to know their family's health history for an understanding of what illnesses may be passed down from one generation to the next. All participants freely commented that in their family cancer or diabetes or high blood pressure or heart disease or stroke was the big killer and "everyone fights ____". They are very much aware that there are some diseases that are passed down and it is important to know what these illnesses are. They recognize the need to be aware of these issues so they can take action against them or to prepare their children with the knowledge so that they will recognize the illnesses in the family.

"As a predictor of what you may be up against regarding that aspect of your health." [1]

"Me and my mother, when my step-dad passed away we found out he had leukemia. Since he was the last of 19 children we do not know who had what. This is my sister's dad. It is kinda my personal health history because it is my sister and I would want to know about that, I want to know everything. He had diabetes and heart problems and she is on the border line of that. I am kinda worried. Since he was full-blooded Indian we want to know if all Indians have this leukemia. We have Indian in us too and I am kinda worried if I am gonna get it." [1]

"Two of my grandchildren's grandmothers died of multiple sclerosis. There is high blood pressure on my mom's side." [1]

"So many diseases are hereditary so you need to know what things run in your family. My sister has a lot of the symptoms my mother had and she died when she was 42." [2]

"To pass that information on to future generations is important." [2]

"I have two kids with sickle cell anemia. I have the trait and my kid's father has the trait and he did not know that." [2]

"I can be able to look out for the disease in somebody else in the family." [2]

"You can teach the children what to look out for." [2]

'Now at every doctor's appointment they ask you.' [2]

"If you do not know your spouses family history you better find out, they always ask you. A lot of it you hear it over and over and I remember it." [2]

Health care

Most participants indicate going to a professional health care worker when they are ill or need some form of medical treatment. Most go to local clinics to see a health care provider and some go to their own gynecologists-obstetricians or other specialists (diabetes). If there is an emergency they go to the hospital and if they have the sniffles they go to the local pharmacy and get a bottle of over the counter medicine. Some have friends or relatives that are nurses who are also called for advice. Very few indicate that they have never seen a doctor or a health care professional. Some are dissatisfied with the health care industry and choose not to go to doctors by choice but admit that when they have a serious medical problem they will seek professional care. Not all participants have health insurance.

"I have a primary care physician and I go to another doctor for my diabetes. When I was a child my grandmother was an LPN, so if it was something minor granny would take care of us." [1]

"At this point in time I go to a primary care doctor. I was the first grandchild of the 5th generation and I do know a lot of home remedies from my grandparents. I can tell you what to do." [1]

"The Elm Street Clinic." [2]

"The Price Hill Clinic can refer you." [2]

"My kids have to go to children's hospital." [2]

"I go to a doctor at UC Hospital, she has had my mother and sister so she knows everything about my family." [2]

"If I really get sick I go to University Hospital. If I just do not feel well I do over the counter. My mom has a doctor that she goes to. She had cancer and he knows her whole history. If I needed to I could call her doctor. But I do not have insurance." [2]

"We do a lot of the old family remedies that have been passed down. When I was pregnant with my first son my mother-in-law thought I had the flu and she was pouring hot toddies and Nyquil down me and it turns out I was pregnant and should not have been taking anything. That is where I go, my mother-in-law. She has a dictionary of grandma's old fashion remedies." [2]

"I do not go to doctors. I go to an OB, but if I am sick I go to my grandma. My aunts an RN and I call her." [2]

Reporting FHH to health care workers

Most respondents indicate that medical professionals have asked them about their family histories and they have shared FHH with a medical professional. In some situations where the person repeatedly goes to the same health care worker, such as a family doctor or the VA Hospital, their personal health history as well as their family health history is known and in their charts. In other cases, where an individual goes to a new or different physician where their

history is not known, most do not have any problem reporting their FHH to the physician if the physician is attentive. {Also see “Health Issues on the Forms” section, p 17}

“I go to the VA Hospital. I got a new primary care physician and I was shocked to sit in her office and she knew everything about me because she read my whole medical history. I was very pleased and she answered every question I asked. It was nice to have a doctor who knew what my problem was. It is hard to re-explain things that have already happened.” [1]

“If it is on the paper because we filled it out as part of the questionnaire.” [1]

“My doctor questions deeply about my depression and anxiety.” [1]

“They ask every time. You have to fill out that questionnaire. They are a doctor and they need to know that, it is OK.” [2]

“They are the doctor and they need to check you out.” [2]

“When I was pregnant, diabetes is a huge thing in my family so they checked me out.” [2]

“I have done it so many times I know the answers.” [2]

“It depends on the doctor, if the doctor is paying attention and listening to what I am saying then I am comfortable. If he is blowing me off then I don’t want to talk to him. When you find someone who is willing to listen to you then it is great but when you get someone who says no, no, no that can’t be it or you are wrong or stupid, then it gets really frustrating.” [1]

Lifestyle issues – do you have control over your health?

Knowing their FHH and actually taking steps to control their health are different issues. Some participants relate stories of family members who changed their lifestyle after a father, brother, sister died of cancer, stroke, heart failure etc. They have lost weight or quit smoking and been proactive in their health. However, while many participants know that they have a history of cancer, stroke, high blood pressure, etc in their families most are not willing to take the steps necessary to change their lifestyles and possibly avoid these health issues. It is not that they are not aware of the fact that smoking can cause cancer and obesity and alcoholism can lead to diabetes and high blood pressure, they are aware of these issues and they will advise their children to not smoke, drink or allow themselves to become obese. They know they can control their own health; however, some are not willing to make these changes in their own lives.

“Yes and you can change your life too. My grandfather’s brother dropped dead of a heart attack at 56 and my grandfather was overweight so he trimmed down and he is doing really good. But his two other brothers just eat and eat and one is diabetic. If you know that there is something in your family like lung cancer then you should not smoke.” [1]

There are some who proactively take steps to avoid certain health issues; they avoid skin cancer by staying out of the sun, they do not smoke or drink alcohol and control their diet to try to maintain a healthy lifestyle.

“Yes, to a certain point. Like your cholesterol. I just found out I have high cholesterol so I watch what I eat. If I found out that I had cancer, what could I do about it?” [2]

“Like diabetes runs in my family, but they were all drinkers and obese. But I have never heard of diabetes in any one in my family who does not drink or over eat. Two of the three that died of diabetes were bar owners and they liked to drink and my mom just liked to drink and she was obese.” [2]

"I think about being in control of my health, loosing weight, quit smoking all that." [1]

"When I have insurance I go to the doctor all the time and make sure I stay healthy. My husband just changed jobs and we do not have insurance right now so we are just trying to maintain until we get it again. My grandmother died at 65 and my mom died at 60. So I spoke to my doctor about that because it is a concern. My cholesterol is extremely high so we determined that was hereditary and I am on that medicine." [1]

"Yes, as far as the family history melanoma cancer is what tends to kill my family. So living in Cincinnati rather than Florida lowers my risk. I am also an indoor person to stay out of the sun. I am a homebody not by choice but to reduce my risk." [2]

There is a fatalistic attitude among a few participants, that there are some issues over which they have no control. If they have a family history of Alzheimer's Disease, Multiple Sclerosis or Sickle Cell Anemia there is not much they can do to avoid those illnesses. However, knowing that it is a possibility and being prepared for it are important issues. Others have a somewhat similar feeling towards heart disease and cancer, also believing that these are unavoidable genetic illnesses.

"To a point you can control your health. In my mother's family there is Alzheimer's. Those of us in this generation laugh and wonder when it will hit us. I do not think I can do anything about that. But there are some things that you can control. What we have to do is make our wishes known to our kids when it hits us." [1]

"I do not think you have control over things you inherit." [2]

"I take care of myself but there is a point where you say God is going to do what God is going to do and I am just going along. I still go after health care, I want to know if something is wrong. I have some control." [1]

"My dad was the type of guy that was when it is your time to go it is your time and he died at 45 from a heart attack and he never went to a doctor. But his brother who was younger, had 5 heart attacks and is still alive. I have treadmill tests whenever I feel bad but I have diabetes from my mom's side of the family." [1]

"Heart disease, no you cannot control that." [2]

"Cancer no, it depends on what kind of cancer it is. Two people in my family died of brain cancer." [2]

"I do not think you can prevent breast cancer." [2]

"I think breast cancer is hereditary. At the same time my aunt and her daughter both had it." [2]

"Everybody on my mother's mother side dies of cancer, either colon cancer or prostate cancer." [2]

Some believe that there are environmental factors which do affect their health. They are exposed to pesticides, lead paint, coal dust and pollutants in the air and water. These are unavoidable realities of life that can result in health issues beyond their control. However, some do take steps to live in a clean environment, eat organically grown produce, avoid pollutants and work in safe and clean surroundings.

"You have to make sure you live and work in a clean house. Not to sit around and be lazy. Get out and get exercise." [1]

"I have a cousin in her 70's in western Kentucky who has had a great life. She worked a farm her whole life. She has breast cancer from the pesticides on the farm crops. I really think that affected her." [1]

"I have control of my environment, I don't use pesticides around the house, things like that." [1]

"I think we get cancer from the stuff they spray on our food." [2]

"I am afraid to buy vegetables in the store, they only have little bitty places with organic vegetables." [2]

The Program

Recommended format

When developing a format for an educational program these participants recommend it to be an interactive discussion group. Participants in both Dayton and Cincinnati expressed an interest in an informal discussion which included a facilitator presenting information. Most would enjoy some formal presentation, such as a video tape or a presenter giving them information to start the discussion, followed by an open forum to discuss what they heard. They like having the opportunity to discuss what was being taught among themselves and also being able to relate personal stories about their lives. By hearing other people tell stories about their lives they often recall information about their own FHH that could be valuable to record. They would like to have forms to jot down names and information about their own family as they remember it during the discussion. Finally most would like to be able to enter the information into the Surgeon General's Software package on-line, save it to their own cd for future changes and print out a hard copy for easy reference.

"I think you should offer it every way – written, video, person to person and let the person pick what is best for them." [1]

"I think hearing it and seeing it, that is the easiest way, you catch everyone, you see it and hear it and take materials home with you." [1]

"This is a comfortable way to talk about this. I learned more here then I do in class." [1]

"Plus you learn that you have things in common, like she has mental illness and I have that in my family as well. It is nice to know that I am not the only one that is dealing with it." [1]

"It would also be more comfortable to put it down on the paper. That is why people are ashamed of things and they do not talk about it." [1]

"It is fun to tell family stories. In a small group like this it is fun to talk about these things." [1]

"This is the right size group and an hour to an hour and a half is good." [1]

"I think 2 hours because in the beginning not many people are talking, you need the first 30 minutes just to feel the comfort. I think you need 1 ½ to 2 hours." [1]

"Let us write down the information first and then put it in the computer." [2]

"It is always better when you have people around you and talk to them." [2]

"A lot of people will just throw away those pamphlets but in a small meeting like this you can talk and learn." [2]

"People are not going to read anything." [2]

"Awareness groups like this are good. A facilitator leading the group would be nice." [2]

"I do not think anyone would listen to an audio tape." [2]

"Getting prepared to come to this meeting, I had not thought about my family history in a long time. Just the thought that I was going to have this conversation made me remember and think about these things. My dad's history, my mom's and my grandparents. I would like a simple form that I could write down what my dad had and what my mom had. Not this specific, something where you can just write it down. I would like a little group like this so we can sit and discuss. You may say my dad had toe-nail fungus and then I may remember something that my mom had from that. Or my little brother had cancer and my father had mental health problems. As we are discussing it may trigger a memory. I would like something more in a storytelling form." [1]

Developing Interest in the Program

On a local level the best way to develop interest in a program would be to present the information as something that would be beneficial for the children. Many comment that they would be less likely to participate if they thought it was for them personally but more likely to participate if they knew that in some way it may help their children.

"You need to stress to people that this is very important for at least their children's history so if you do not know about your family then investigate other family members so that you have information. If you do not know about your dad you may find out about his brother or sister." [1]

"I would talk to her about her children. My little brother died of non-Hodgkins lymphoma when he was 25. So when my sister found out the first thing she did was have all her boys tested. If I had not shared that information with her she would not have known to let her sons know. It could be hereditary." [1]

"In my opinion you need to know your family health history because of the hereditary things that are passed down – the big things that can be passed. Like adult onset diabetes." [1]

"When you end up with cancer when you are 30 or 40 years old you will not know how you got it. It might have been something in your family history." [2]

"If one of your children pops up with something that you never heard of you know it comes from the daddy's side." [2]

"I would tell you it is important to know because you need to know what is going on in your family for your kids and grand kids." [2]

"Before I had kids I did not care. Now that I have kids I am not losing my babies, they are more important than my life." [2]

"I think if they would stress more about mother's teaching daughters and sons and when you get married learn from your in-laws. It should be stressed family talking to family. It has to be more of a family thing, talk to your in-laws." [2]

On a national level, if a celebrity such as Montel Williams, Oprah Winfrey or Maury Pouvich did one of their shows about the importance of FHH that would peak the interest of many people. All agree that if they saw a television show on this topic they would be more likely to attend a program to learn more and to help them record their FHH.

"Media attention, something on the Discovery Channel would help. If that aired it would be better than coming and watching a video tape." [2]

"If I saw Montel Williams doing a show on this it would be much more interesting than a video." [2]

"I would watch that. I watch Discovery Health all the time. Tyra did a show not too long ago about how much you do not know about sex. It is because of someone who is popular that you listen to them. Maury does a lot of shows like that too." [2]

Surgeon General's Family History Initiative – paper tool

Section 1 – What information do I need?

- **Talk directly to your relatives**

This section was well received – very little discussion. No disagreement.

"Absolutely, this is a definite." [2]

- **Ask about any health conditions they have had.**

Also very little discussion about this section. It is clearly written and easy to understand what needs to be done.

"That's a good one, keep that." [2]

- **If possible, list formal names of conditions**

Very intense discussion regarding the recording of medicines taken by family members. Most agree that this is too much information and they are not likely to be able to get the names of the medicines their family members take. Some comment that they cannot remember all of the medicines that they personally take so knowing this information about relatives is highly unlikely. A few also point out that for some diseases, such as Crohn's Disease, there are no medicines and in some cases the same medicine can be used to treat a number of different conditions.

"That would be hard to list medicines. Unless you really know." [1]

"If they have been taking the pills for years or if you set out their pills for them then you would know. This would be too hard to get." [1]

"I had to go to the emergency room last year and they asked me what medicine I was on and I could not remember the names of what I was taking." [1]

"I do not know about the medicines. How would you know this?" [2]

"You are not going to know who is talking what medications in your family. You have to know too much here." [2]

"Certain people can take some medicines and other people take something different for the same diseases." [2]

"This is too much information. I think all of it is fine except the medications." [2]

"Some conditions are not always medicines, like Krohn's Disease there is not medicine." [2]

- **Get help finding information**

Again this section is asking for information that is not obtainable. With the new HIPPA regulations in place no one has access to other people's medical records. It is impossible to ask doctors to see family members' medical records. All agree that the best they could do is get a

copy of someone's death certificate to learn the cause of death, but that may not be enough information, nor can it always accurately give them the FHH information they need.

"How easy is it to get copies of medical records?" [1]

"I do not think you can get medical records. I would like to have copies of medical records for my dad and they will not release that. They would not even give me his death certificate." [1]

"This is not doable because of the HIPPA Act. There is no way you can get info, not for your husband or nobody unless you have the Power of Attorney." [1]

"Medical records is way too personal." [2]

"I do not think HIPPA regulations would let you get that." [2]

"If they are deceased you cannot get that information either." [2]

"It is the medical records part. Trying to get someone's medical records, unless it is a spouse you can't get that." [2]

Another problem associated with this directive is the fact that many older relatives did not go to doctors or their medical history was not recorded. Most participants agree that they can only go as far back as parents or possibly grandparents. Many would ask for assistance from other family members such as older siblings or grandparents to get this information.

"A lot of my family live in Hazard and they did not have medical records, I think it would be so difficult to find that." [1]

"You are talking about years ago, they did not have doctors, there were midwives and there were no records turned into the proper places. That is why it is difficult to get birth certificates and things like that." [1]

"What if they are too far back in the family history when they did not keep medical records." [2]

"There is a lot that I do not know about my family. I would try to put in what I knew." [2]

"I would put down some stuff like about my parents." [2]

"I would give this to my grandmother and let her do it." [2]

"I would go talk to my older sister, just because she has 10 years on my. She has been around." [2]

- **Are you planning to have children?**

This is an important point, but again, getting the information (particularly about the father(s) of participants' children) is not always possible.

"That will be for a lot of people, it will be impossible to get that information." [2]

"I would try to fill it out as well as I could, this is for the children so they know what is going on for their children. So they know what is being inherited." [2]

"If everybody can get their own and keep it, that is important." [2]

Section 2 - Talk to your family

Defining which family members to include in the family history will be an important point during the educational program. Some participants do not understand the need to include

siblings or nieces and nephews in their FHH. They are taking the word history very literally to mean only the people that came before them.

"That bothers me. If I am giving my doctor my family's health history, my grandparents, parents, aunts and uncles, the ones who came before me, what happened to them medically as opposed to the ones that are lateral like brothers and sisters and cousins. We are talking history so we are going back to whoever came before us." [1]

"But in talking to your family, like in the case of my little brother it was important for me to let my sister know so that my nephews could get tested. Now my nephews know to watch out for that, so I think nieces and nephews fall into that." [1]

Section 3 - How do I fill out the form?

- **Write each of your relatives names in the designated boxes. Circle whether they are male (M) or female (F).**

The form *My Family Health Portrait*, is only workable for less than half of the participants in this research. All agree that it is a good form for a small, uncomplicated family. However, in the situation of large families with multiple fathers and many half-sisters and half-brothers and siblings who are also cousins, this form does not work. The majority believes that they need to record their entire family tree including all members of all sides of all families.

- The lines are too small to record all the necessary information
- There are not enough boxes to list all family members
- The instructions are not clear how to indicate blood relationships. Specifically the instructions regarding twins is very complicated and not easily understood
- There needs to be a way to record different fathers for children on the same form

"This works for a small family or a family that is not complex this is fine. My family would be easy to do this, no divorces in the family, so it is very conventional." [1]

"This is good for a small, uncomplicated family. This has to have connections between aunts and uncles and cousins. This is impossible to come up with a real picture of the family." [2]

"If they wanted me to list only the aunts and uncles with medical problems that might be OK. But if I was to list all of my relatives then I need more space." [1]

"You need options for multiple fathers for the children." [1]

"It needs a lot more space." [1]

"My boyfriend now is not the father of my children and I would put him in that space." [1]

"If it is my family history I do not need my spouse and children in there anyway. It should be a history of what is coming down the line to my children." [1]

"I think it should be a paper for you and your family history and then another one for your children and then another one for your spouse." [1]

"This is just too complicated." [1]

"I am having trouble with this. My two oldest kids and two youngest kids have different dads, so do I put same mom or same dad or what do I do here? They have the same mom but different dads. This is very confusing." [1]

"Where do you put the grandparents of kids with different fathers? I do not like this." [1]

"This is not working for me, it is not enough." [1]

"That is not clear, really there are 50 million first lines on here. Where am I supposed to write this stuff? So which first line are they talking about?" [2]

"And if they are talking about half brothers and half sisters, personally in my family, half-brothers are also cousins in some cases. My husband's half-brothers are cousins, they are brothers and cousins at the same time. Families get complicated especially the more southern they are." [2]

"We need branches that connect. If you go by blood they are blood brothers and technically they are cousins too, that is a lot of explaining." [2]

"All they have here is a spouse/partner. They do not have a section for the right mother or father. They also do not have anything for the spouse's side of the family and that is important too." [2]

- **On the lines under the boxes, write the names of any health conditions your relatives have had.**

All agree that this is the purpose of filling out the form and it is important to fill in any medical history for each relative.

"That is very important to know. My husband is only 34 and he has had two strokes back to back. His father had a major heart attack when he was 36 and his uncle had one at 35 and everybody said they were too young to have that. It is in the blood family. It is very important to know this." [2]

- **Once you have completed the form, take it to your health care professional.**

Most agree that they would take this form to their doctor; however, they are very skeptical that it will be looked at. They believe that the health care professionals they go to, i.e. clinics and emergency room doctors would not be interested in the information on this form because it is difficult for them to read. Most physician offices have their own forms for FHH so they would not be interested in using this form. The information on this form is more useful for the individual's own personal information.

"This is too complicated for a health care professional. They have their own forms and they would not even look at this." [1]

"It would go right in the trash can." [1]

"This would be a waste of time to take it to the doctor, it would be nice to have for myself as a resource." [1]

"Then you can give it to the rest of the family and bring it with you when you went to the doctor." [1]

- **Make a copy for your records.**

This is a form that most would keep to pass on to their children. It is a written method to keep track of the family history.

"It would be nice to keep it and pass it down to the rest of the family that they would know the history that you knew of deceased relatives." [1]

"Where is says to make a copy for your records, I am all for that." [1]

"We could print it out and save it for our children so they can have it when they need it." [1]

Health Issues on the forms

Overall most agree that they would be willing to include all health issues on the forms, there really is nothing that was indicated as too embarrassing to discuss. There are however some who would not be willing to tell their doctor about certain family health conditions. They are concerned that if a health professional knows they have a family history of mental illness or cardiovascular disease, then they will only look for those conditions and not assess the individual's personal health needs.

Some also suggest that lifestyle needs to be included on the forms. If someone who smoked dies of lung cancer or someone who worked in the coal mines has emphysema, those are important points to record.

"I think they should add mental illness to the list." [1]

"Mental health should be talked about. This is for your doctor and your own personal information so I would put it down." [2]

"I would not put anything on here that I did not want my doctor to know about. I would not want him to know that my mother was depressed. If I feel that I needed attention for depression then maybe I would tell him. But if I do not think I am depressed then I would not tell him that my mother and aunt were clinically depressed. You do not want him looking at you like you are crazy. Like I have bad genes in me or psychological problems when I do not." [2]

"More than likely they will ask you if you have any of those symptoms? And then they evaluate you on that without you even saying you want to be evaluated for it. You can just be sitting there talking to them and they think you are crazy." [2]

"I would tell them because they need to know it." [2]

"I have cousins that have bipolar but that does not mean I have it. I would not tell my doctor that my cousin is schizophrenic or bipolar because they will ask me that question. A lot of people have schizophrenia and bipolar but they have control over it because they were never diagnosed with it." [2]

"If it was for my own personal records you could put it on the form." [2]

"Looking back I would put it on my records that I had depression after my first baby but really they were not doing their job either. They should have noticed that I was depressed, that I was not holding my baby and that I did not want nothing to do with him. That is something they should have picked up on, I did not think they did their job." [2]

"If your mother had diabetes or your father had skin cancer, you have to talk about their lifestyle habits too. If they smoked or if they were out in the sun a lot or if you are a coal miner." [2]

"You need to put occupation and if they are drinkers or smokers on the form too." [2]

Surgeon General's Website – www.familyhistory.hhs.gov

Internet access

The majority of participants from each group indicate that they have internet access. Many have home computers or access via a relative's home computer. Others go to the library or

other public institutions such as schools and universities to get on the internet. Some use the computers at local community centers to access and research information.

There is some concern about entering information directly on-line. Even though there is a confidentiality statement upon entering the website most would be more comfortable if they were able to enter their personal information off-line and keep it stored on a separate disc. Even though the website says confidential, there are enough instances of stolen personal information that individuals do not want to risk their personal health information leaking to other sources.

"How confidential is it?" [1]

"I would feel comfortable doing this because I do not see that there is any information that would hurt you." [1]

"But what if it affected your job or your children's job?." [1]

"When I went into the Air Force they wanted to know about me to give me a security level. What if they used this to decide on security level? They probably could do that." [1]

"I would not do it in a library or on a public computer. I would want to do it in a more private place." [1]

"I think more people would do it if they sent you a disc in the mail, if people are afraid of on-line things or to download programs. If they sent you this disc it feels safer. Then you do not have to connect to the internet at all." [1]

"I like the idea of this but I want to keep it on a disc and update as needed." [1]

Internet tool

Participants from both groups agree that they prefer entering the data on the electronic tool. While many indicate that they would like to have a worksheet to start the process; a formalized sheet for them to record all family members and any health history they can recall, they also would like to enter the information into the electronic tool for the family tree printout and the final listing of the family members.

The advantages of the internet tool:

- Can accommodate very large families
- Can accommodate complicated families
- Can easily be modified and updated
- Can be printed for distribution among family members
- Easier to take to a doctor and attach to medical records

"That one looks better than the one on paper. It has more of the history, more space for the actual history." [2]

"This is so much easier than writing things out." [1]

"It actually has more information." [2]

"This makes it easier to organize." [2]

"To have that form (the final printout) to make notes as you are talking in a small group discussion like this and then you can go back and put all the information into the computer. That would be good." [1]

"Take the worksheet home and fill it out and then bring it back." [1]

“That would be easier to take to a doctor’s office rather than a tree.” [2]

“The doctor could attach this to my chart.” [2]

“The tree is good to have for your household and the printout is easier to bring to the doctor’s office.” [2]

“It would also be easier to keep updated when there is a child added to the family. You can add the child to your list and if the child is also part of another family they can be added to that one too. It is easier to keep track.” [2]

Informational Printouts

Participants in Cincinnati were asked to select one of the following four printouts that they thought was the most visually appealing:

- The University of Utah – Learn.Genetics
- Minnesota Department of Health – Breast Cancer and Family Health History
- Cancer and Family History
- Minnesota Department of Health Fact Sheet - Family History and Cardiovascular Disease

Overall the printout that is most visually appealing is the University of Utah – selected by 10 of the 12 participants. It is by far the most colorful and visually attractive. It was very difficult to get participants focused on the visual appeal of the printout and not the topic; some were attracted to other printouts because of the information presented. It is difficult to assess whether they were attracted to this form because of the visual appeal or the topic of genetics.

“Learn genetics. Genetics and the different diseases, the heart disease, asthma, diabetes all just stood out. Hardly nobody thinks of asthma as a problem. That is one that don’t stand out.” [2]

“This one stands out more and when you see the word genetics, you automatically know that that is your family history.” [2]

“I understand what the word genetics mean. High school kids and adults know what genetics are. My son watches all those shows like CSI and he already knows what genetics and DNA and all that stuff is.” [2]

A few selected the Minnesota Department of Health – Breast Cancer and Family Health History printout. This printout is colorful and visually has a lot of movement on the page but it is impossible to determine if the individual is attracted to the layout or the topic.

“I did a report on breast cancer when I was in school and I thought it was interesting that it was about breast cancer. I like to read things with lots of colors.” [2]

“I think breast cancer is them most important thing to read about. If the other one was about breast cancer (U of Utah) I would have picked that one.” [2]

Cancer and Family History was selected because of the photograph of the interracial family – it attracted attention.

“It was the interracial family on the front that caught my attention. I only have a few family members that are interracial but it caught my attention. I think blacks and whites are genetically different and it caught my attention and I wondered how that related to cancer.” [2]

The least interesting of the four handouts is the all black and white sheet from the Minnesota Department of Health Fact Sheet. There is too much reading, it is boring and not visually appealing. However, once again it may have been the topic and not the appearance that put this one on the bottom of everyone's list.

"There is no color, it is boring." [2]

"Plain, bland." [2]

"It is about vascular disease so the topic is not interesting." [2]

"The topic may be great but the visual is too plain." [2]

"When you go to a doctor's office you grab the moist colorful pamphlet because it attracts your attention." [2]