

FINAL REPORT

**Submitted to:
Education and Community Involvement Branch
National Human Genome Research Institute**

**Developing Community Based Models for Education and Utilization
of Family Health History Information: A Demonstration Project in
Urban Appalachian Communities**

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Abstract

Purpose: To engage and educate women in urban Appalachian communities about the importance and use of family health history.

Target Community: Urban Appalachian women 18 years of age or older with less than a college education who reside in the Greater Cincinnati/Northern KY and Dayton metropolitan areas.

Project Goals: 1) engage the target community to create and/or expand existing family history materials to fit the needs of the Appalachian community, 2) engage a minimum of 100 females from the Appalachian community in completing “My Family Health Portrait” through participation in two education sessions, and 3) increase awareness of the importance of Family Health History among health professionals working in health clinics in the geographical areas targeted in the Family History Demonstration Project.

Methods: Low literacy family health history materials were developed after holding two focus groups of 8-10 participants. Additional participants were recruited by one of six community organizations that provide services to the target community to participate in two education sessions about the importance of family health history in preventing disease. Participants recorded their family health history using the Surgeon General’s family history tool “My Family Health Portrait” during the first education session and updated it during the second. The education sessions were evaluated with written questionnaires after each education session.

Results: One-hundred women attended one of 13 initial education sessions held at the community organizations. Ninety-two returned to a second education session. All 100 women were able to complete their family histories electronically or on paper using “My Family Health Portrait.” Family history resources developed for the project were evaluated positively by participants. The education sessions were successful in teaching participants the importance of family health history, and how to complete their own family histories. However only 67% of participants felt they had enough training to find the form on the web and less than half felt they could teach a family member to find the form.

Discussion: Education sessions were successful at teaching urban Appalachian women with less than a college education about the importance of family health history and how to take their own family histories. However, not all women felt they could find the Surgeon General’s tool on the internet suggesting access may be a barrier.

Key Words: family history, family health history, Appalachia, community-based participatory research, My Family Health Portrait, health literacy

**Developing Community Based Models for Education and Utilization of Family Health
History Information:
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Executive Summary

Family health history (FHH) is promoted as a tool to improve health and prevent disease. Although FHH tools and resources about the importance of FHH exist, few resources are available for individuals with low literacy skills who might be medically underserved. In September 2006, investigators from the University of Cincinnati, Cincinnati Children's Hospital Medical Center, the Ohio State University, Sinclair Community College, and community organizations including the Urban Appalachian Council and Lower Price Hill Community School in Cincinnati, OH, Brighton Center in Newport, KY, and Sunrise Center, Voices of America, and Life Enrichment Center in Dayton, OH partnered together to educate urban Appalachian women in Southwest Ohio about the importance and use of FHH in improving health and preventing disease.

Goals of the project were to 1) develop and disseminate low literacy educational materials about the importance of FHH in promoting health and preventing disease, 2) educate the target community about how to collect family history information (including how to engage family members in the collection) and how to access and complete the Surgeon General's Family History Tool, and 3) increase awareness about the importance of FHH information among health professionals working in health clinics in the targeted areas.

Focus groups with urban Appalachian women were held to understand how this community defined FHH, what they perceived the importance of FHH to be, and how they would like to learn about FHH. Findings from the focus groups guided the development of the resources used through-out the program.

Thirteen groups of 5-13 women participated in two education sessions held two weeks apart. Education sessions were held at four different participating community organizations. In these sessions, women learned about the importance of FHH as a risk factor for common chronic diseases, how to collect and document their own FHH using "My Family Health Portrait", and how to talk to healthcare providers about their family history.

Education Sessions

All participants completed their FHH online or on paper. The education sessions were successful in teaching participants the importance of family health history. However only 67% of participants felt they had enough training to find the form on the web and less than half felt they could teach a family member to find the form.

After each education session, participants were asked to indicate how satisfied they were with the location of the session, the length of the session, and the facilitator who led the session. Eighty percent were very satisfied with the length of the first education session, 89% were very satisfied with the location of the first education session, and 93% were very satisfied with the facilitator. After the second education, 79% were very satisfied with the length, 95% were very satisfied with the location, and 98% were very satisfied with the facilitator.

Satisfaction with the education sessions was high. Evaluations conducted after the education sessions indicated the sessions were successful at teaching urban Appalachian women with less than a high school education about the importance of family health history and how to take their own family histories. However, not all women felt they could find the Surgeon General's tool on the internet suggesting access may be a barrier. Further research is needed to determine whether consumers take their FHH to providers after participating in a family-history education session and how providers use this information.

**Developing Community Based Models for Education and Utilization of Family Health
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I. Project Overview

In November of 2004, U.S. Surgeon General Richard H. Carmona, M.D., M.P.H., in cooperation with other agencies within the U.S. Department of Health and Human Services launched a national public health campaign, called the U.S. Surgeon General's Family History Initiative, to encourage all American families to learn more about their family health history (FHH). As part of this initiative, the Surgeon General created a computerized tool called "My Family Health Portrait" to help consumers create family health histories. This tool is available electronically or in print to those with computers connected to the web with an up-to-date version of a major Internet browser.¹ However, access to this tool and comprehension of the available family health history materials is likely to be limited in a population with low literacy skills, such as the urban Appalachian communities in the Greater Cincinnati and Dayton, OH metropolitan areas.

In keeping with the mission of the Education and Community Involvement Branch (ECIB) of the National Human Genome Research Institute (NHGRI) to develop education and community involvement programs to engage a broad range of the public in understanding genomics and its translation to health and society², we worked with the urban Appalachian communities in the Greater Cincinnati/Northern Kentucky and Dayton, OH areas to develop and disseminate a model program that engages and educates urban Appalachians about the collection and use of their own family health history.

II. The Target Population

Greater Cincinnati/Northern Kentucky Urban Appalachian Population

The federal Appalachian Regional Commission (ARC) has defined the Appalachian region as 410 counties in 13 states.³ Approximately 34% of Greater Cincinnati is Appalachian⁴ and at least 10 urban neighborhoods have been identified as Appalachian.⁵ Although about 10% of urban Appalachians hold managerial or professional jobs, they are predominantly a blue collar group.^{5,6} The urban Appalachian neighborhoods consistently experience some of the highest dropout rates in Cincinnati with rates approaching 100% at some schools.⁷ In 2000 the high school dropout rates ranged from 11%-58% in the 10 Appalachian neighborhoods, between 21%-62% of adults 25 and older had less than a high school diploma, and between 3%-26% were functionally illiterate. A 2002 Greater Cincinnati Community Health Status Survey in 22 counties of the Greater Cincinnati area, which includes Northern Kentucky, assessed the health status of over 2000 randomly selected adults. Self-identified first generation white Appalachian participants in the survey were more likely than non-Appalachian whites and African-Americans to report having chronic lung disease (6.9% compared to 3.4% and 2.4%), diabetes (12.5% compared to 6.0% and 9.8%), heart trouble or angina (10.8% compared to 9.7% and 7.0%), high blood pressure (44.2% compared to 25.4% and 29.8%), high cholesterol (35% compared to 23.2% and 14%), and stroke (6.2% compared to 1.6% and 0.4%). Cancer rates were similar to that of non-Appalachians whites.⁸

Dayton Urban Appalachian Population

There are several Appalachian communities in and around the Miami Valley-Montgomery County-City of Dayton region (about 60 miles north of Cincinnati). The largest concentration of Appalachians, however, remains the east side of inner city Dayton which was the original port-of-entry during the migration period from the 1920s through the 1960s. According to the 2000 U.S. Census data, the population of east Dayton (which is comprised of several smaller neighborhoods) is approximately 60,000. Residents are predominantly Caucasian (92%) with the vast majority being of Appalachian descent. More than 38% of the adults have less than a twelfth grade education (10% have less than a ninth grade education), and 63% are unemployed (11%) or not in the workforce. The children in these families are at-risk – academically, socially, and health-wise.⁹

III. Project Goals and Methods

To develop and disseminate a model program that engages and educates urban Appalachian women about the collection and use of their own FHH, our goals were:

1. To engage urban Appalachian women 18 years of age or older who reside in the Greater Cincinnati and Dayton metropolitan areas, and experts in developing low literacy materials, to create and/or expand existing family history materials to fit the needs of the Appalachian community and other communities with similar low health literacy characteristics.

Early in the project, a conference call was held with the Family History Working Group and members from each participating community organization (see Sections IV and V) to discuss cultural aspects unique to the urban Appalachian community and the best way to engage them. Some of the themes and suggestions that emerged from this conference call were:

- Many members of the Appalachian community are storytellers, so be prepared to listen.
- It's important to communicate to participants that the information they can provide has value because their accomplishments are not often valued or treasured outside their culture.
- When explaining the project it was suggested that we explain that medical information is not easy to understand and we are trying to develop materials that everyone can understand.
- Fatalism - participants may feel that their health system is not responsive to their needs and therefore they cannot prevent disease.
- Powerlessness – is a theme that grips the culture and it may be hard for participants to volunteer things they can do differently to make their personal health better. However, people are much more forthcoming with information when talking in the context of family (particularly children). They may have given up on themselves, but they still have hope for their children to find a way up/out.
- Strong family bonds – at a recent Thanksgiving luncheon attended by a Family History Working Group member, the most common response for what members of the Appalachian community were thankful for was “family”, but family included friends/neighbors.

The above information influenced many aspects of the project. For example, to develop culturally appropriate materials, the Cincinnati Family History Working Group began by holding two focus groups each with 12 members of the target community. Both focus groups were led by the same professional focus group moderator who participated on the conference call described in the above paragraph to learn about cultural aspects of the urban Appalachian community. To reinforce the message that participants' voices would be "heard" and valued in other cultures, the focus group facilitator assured participants in her introduction that:

"...people [will] listen to what you have to say. What we discuss here will make a difference in how the program my colleagues are developing will run and what they will talk about and what materials they use. This is not something that will only be used here, the plan is for them to make the information we learn from you available to other communities and groups around the country. So what you tell me today will have a large impact on a lot of people."

One focus group was held at a participating community organization (PCO) in Dayton, and the other at a PCO in Cincinnati. All participants were recruited by representatives of the PCOs. Participants were asked what they perceived "family health history" to mean, what they perceived the importance of FHH to be, and how they would like to learn about it. They were also asked what types of materials (print, online, audiovisual, or other) would engage the community. Participants were asked to look at available family history resources and to provide input on their perceptions about adaptations needed to make them more useful for their community members. The final report summarizing the focus groups is included in Appendix 1. The information and insights gained from the focus groups were used by the Family History Working Group to develop culturally appropriate educational materials regarding family health history to engage and educate the Appalachian community. The materials were included in a FHH resource packet distributed during the first education session and evaluated during the second education session. A description of the evaluation process is included in the "*Evaluation of fact sheets developed by the Family History Working Group*" below. Copies of the final fact sheets are included in Appendix 2 and are available at (<http://www.cahts.uc.edu/gc/Fact%20Sheets.htm>).

2. To engage a minimum of 100 females from the Appalachian community in completing "My Family Health Portrait" through participation in two education sessions.

Each education session was facilitated by Dr. Melanie Myers collaboratively with a representative from the PCO. The representative from the PCO was valuable in helping gain trust with participants. Representatives from the PCOs recruited women to participate in the education sessions. Eligibility requirements included being over 18, having less than a college education and any of the following: the participant, a parent, or grandparent either self-identifying as Appalachian or being born in a Federally-designated Appalachian county. Literacy levels were not formally assessed as the PCO representatives felt it would stigmatize participants and make them feel uncomfortable. Instead education level was used as a proxy for literacy.

Learning objectives for the education sessions were developed by the Family History Working Group and a professional evaluator in keeping with the objectives of the project and the ECIB Request for Proposals. Questionnaires were developed by the Family History Working Group with input from the professional evaluator to assess whether the learning objectives were met in each of the education sessions. Questionnaires were then completed by participants at the end of each education session(s). The community representative read each question and response item out-loud with participants and then asked each participant to mark her answer on the questionnaire. This allowed an anonymous evaluation that did not preclude participants with low literacy skills from completing the evaluation. Responses were analyzed in SPSS 15.0. A chi-square test was used to calculate differences in proportions.

The two education sessions are described below:

Education Session I:

In the first half of Education Session I, participants learned about the importance of FHH in risk assessment and health promotion. In keeping with the objectives specified in the ECIB Request for Proposals, Education Session I focused on increasing awareness of the importance of collecting family history information, informing participants how to access the Surgeon General's Family History tool, and educating participants about how to collect family history information (including how to engage other family members in the collection). PowerPoint presentations were developed or modified with input from the Family History Working Group to convey the aforementioned information. Existing slides from the Surgeon General's FHH Initiative were used or modified when possible. All presentations were reviewed by the Family History Working Group for content and by Dr. Sandy Cornett for literacy level. The first presentation gave a general overview of the importance of FHH and how it can be used to improve health and prevent disease. As part of this presentation, an example FHH was recorded on a poster-sized paper version of "My Family Health History" to demonstrate how to complete a FHH on paper. The second presentation provided an overview of the six diseases covered in "My Family Health Portrait" and the role of family history as a risk factor for these diseases. The third presentation reviewed how to access and use "My Family Health Portrait" electronically. Rather than ask participants to memorize a website, we showed them how to Google "My Family Health Portrait." In addition, screen shots of the electronic version of the tool helped demonstrate how to navigate through and complete a FHH electronically. A fourth and final presentation focused on talking with family members to collect FHH information and reviewed the type of information that should be collected. All four presentations are included in Appendix 3.

After the presentations, participants were given time to complete the electronic or paper version of "My Family Health Portrait." Facilitators (the PI, the community representative, a graduate student, and/or 1-2 additional members of the Family History Working Group) were available to answer questions and help with completion of the FHH as needed. Participants who chose to complete their family history electronically received a saved copy of their family history on a CD. Participants who completed their FHH on paper, took the original copy with them. A copy of each participant's family history was also kept by the PI.

In keeping with the Surgeon General's Family History Initiative, participants were encouraged to take their completed family histories home with them to talk with their relatives about health conditions that run in the family. Participants were instructed to return to the second Education Session with their family histories.

Learning objectives by the end of the first education session were for all participants to be able to:

1. Record, using the Surgeon General's "My Family Health Portrait" family history tool, their FHH (electronically or on paper)
2. Identify the importance of FHH awareness in promoting health and preventing disease
3. Explain how to access "My Family Health Portrait" using the Internet
4. Identify at least four relevant questions to ask relatives to collect FHH

Education Session II:

The second education session took place two weeks after Education Session I. A two week period was chosen to allow participants time to consult with family members but not so much time that they forgot about the project. PCO representatives phoned participants prior to the second education session as a reminder. The same facilitators who led Education Session I also led Education Session II. Much of the second education session was spent on group discussion. For example, the facilitators generated discussion regarding with whom participants shared their FHH's and fact sheets in the previous two weeks. Participants were also systematically asked about any challenges or difficulties encountered by participants and any questions generated when trying to collect additional health information from family members. Based on advice from the PCO's, a handout was developed and time was spent discussing how to talk to health care providers (see Appendix 4). During Education Session II, participants were also given time to update their family history with new information they obtained since the first session. Copies of completed family histories were again collected by the PI to evaluate any new information participants collected and recorded between Education Session I and II.

Learning objectives specific to the second education session were for all participants to be able to:

1. Report problems they encountered while gathering their FHH from family members
2. Report how they intended to use the information they gathered to promote the health of themselves and their families
3. Confidently ask questions of a health care professional about FHH for the improvement of their families' health

3. To increase awareness of the importance of Family Health History among health professionals working in health clinics in the geographical areas targeted in the Family History Demonstration Project.

Prior to Education Session I, 15 health clinics were mailed information about the Family History Demonstration Project and were informed that women participating in the project might contact them about their family health history. Health clinics were selected based on their

proximity to PCO's, suggestions from PCOs, and available information about populations served by the health clinics. The mailed announcements contained web addresses of available family history resources to improve health professionals' knowledge about interpreting family histories as well as copies of the fact sheets developed for the project and a sample family health history. Family health history resources identified in the mailing included:

- a. The Cincinnati Children's Hospital Medical Center Genetics Education Program for Nurses' (GEPN) "Interpreting Family History" self-paced module (<http://gepn.cchmc.org>)
- b. American Academy of Family Physicians Family History Program (<http://www.aafp.org/online/en/home/clinical/acf/genomic/acfgenomics/famhxprogram.html>)
- c. March of Dimes Genetics and Your Practice, "Family Health & Social History" (<http://www.marchofdimes.com/gyponline/index.bm2>)
- d. National Coalition for Health Professional Education in Genetics, "Genetic Family History in Practice Newsletters" (<http://www.nchpeg.org/content.asp?dbsection=newsletter>)

Health professionals were also offered an in-service about FHH and were instructed to contact Dr. Myers if they were interested in an in-service.

4. To disseminate results nationally through publication of findings in one or more peer-reviewed journals and presentation of findings at national meetings and conferences.

Findings from the project have been presented at the 2007 National Society of Genetic Counselors' Annual Education Conference, and at the 2008 CDC 10th Anniversary of Public Health Genomics Meeting. Copies of the abstracts and posters are included in Appendix 5. Efforts to publish the findings and processes of the Family History Demonstration Project are underway.

IV. Participating Community Organizations

Six PCOs that provide services to urban Appalachians participated in the Family History Demonstration Project and are listed below. These organizations were crucial to engaging and educating the target community. They also were vital to educating the Family History Working Group about the culture of the urban Appalachian community. Relationships with these PCOs were facilitated through members of the working group who had established working relationships with the PCOs. A positive working relationship with the representatives of the PCOs was fostered through open and honest communications and by recognizing that the representatives of the PCOs were the experts on engaging and working with the target population. In addition, the PI visited each PCO to discuss the project and routinely included the PCOs on email updates about the project. All six PCOs recruited participants to the focus groups and the education sessions. Four of the six PCOs also provided space and access to networked computers for the education sessions. The six participating organizations included:

Brighton Community Center
PO Box 325
Newport, KY 41072-0325

The Brighton Center, Inc. is a non-profit agency whose mission is to create opportunities for individuals and families to reach self-sufficiency through family support services, education and leadership throughout the communities of Northern Kentucky (www.brightoncenter.com).

Life Enrichment Center
515 North Irwin Street
Dayton, OH 45403

The Life Enrichment Center is a faith-based, non-profit organization working in collaboration with area wide partners to provide life building, life sustaining services to the underserved in the greater Dayton area (<http://www.daytonlec.com>).

Lower Price Hill Community School
2104 St. Michael Street
Cincinnati, Oh 45204

The Lower Price Hill Community School (LPHCS) is a modern learning center that removes barriers to education, provides instruction and guidance in a supportive and familiar environment, and assists individuals in meeting their educational and employment goals (<http://www.lphcs.org/index.htm>).

Sunrise Center
Site Coordinator, Southeast Weed and Seed
1320 E. Fifth St
Dayton, OH 45402

The Dayton Southeast Weed & Seed Initiative is an initiative to “weed” out crime and drug trafficking in neighborhoods in northwest Dayton - and then to “seed” that area with programs for youth, families, and seniors (<http://www.daytonnorthwestweedandseed.org/>).

Urban Appalachian Council
2115 W. 8th Street
Cincinnati, OH 45204-2003

The Urban Appalachian Council is a non-profit, social service organization that provides direct and advocacy services in communities of Cincinnati most heavily populated by Urban Appalachians (<http://www.uacvoice.org>).

Volunteers of America of
Greater Ohio Community Center
2601 E. Fourth Street
Dayton, OH 45403

The Community Center of Volunteers of America (VOA) in Dayton, OH is a non-profit community organization that provides educational and social services to the heavily Appalachian population of East Central Montgomery County (www.voacentralohio.org).

A representative from the Brighton Center in Newport, KY, the Sunrise Center in Dayton, OH, from the Urban Appalachian Council in Cincinnati, OH, also served on the Family History Working Group.

V. Cincinnati Family History Working Group Members and Expertise

Dr. Melanie Myers – project PI

Dr. Carol Baugh – expertise conducting research and working with the PCOs and the urban Appalachian communities in Dayton, OH

Dr. Katie Brown – expertise conducting research and working with the PCOs and the urban Appalachian communities in Cincinnati, OH

Dr. Sandra Cornett – expertise in health literacy and Director of the Area Health Education Center (AHEC) Health Literacy Program at The Ohio State University.

Ms. Bonnie Hood – representative of the Urban Appalachian Council in Cincinnati, OH

Ms. Norma Ryan – representative of the Sunset Center in Dayton, OH

Ms. Paula Houston – representative of Brighton Center in Newport, KY.

Ms. Cynthia Prows – expertise in developing and providing family history education to health professionals

Ms. Nancy Warren – expertise in cultural competency and extensive experience working with minority populations

Ms. Margaret Au – genetic counseling graduate student

Ms. Jody Wallace – genetic counseling graduate student

Consultants:

Ms. Kathy Glandorf – focus group moderator

Dr. Judy Jarrell – professional evaluator

VI. Project Results and Evaluation

Focus Groups

As mentioned in Section III, prior to developing the educational program, two focus groups were held with the target community to determine how urban Appalachian women defined FHH, what they perceived the importance of FHH to be, and how participants would like to learn about FHH. Twenty-four women between the ages of 20 and 64 participated in one of two focus groups. Sixty-five percent reported having a high school education or less, 79% self-identified as white and 79% had children. When asked, most defined FHH as the health or illnesses that reoccur in the family... *“[it’s the] illnesses that reoccur in your family line. Like hypertension, diabetes, heart trouble.”* The participants recognized that you had to be related by blood when considering risks associated with FHH... *“If they are not blood, then your health is not mixed in with them.”*

Focus group participants felt the importance of knowing FHH was to understand what illnesses may be passed down from one generation to the next... *“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.”* They recognized the need to be aware

of FHH to take action or recognize the illness in a family member...*“It’s a predictor of what you may be up against so they can be more careful in that aspect of your health.”*

When developing a format for a FHH educational program, participants recommended an interactive discussion group led by a facilitator...*“A lot of people take the pamphlets and throw them away...But if you’re in a small meeting like this, everybody’s like ‘ok’ sit back and listen”* and stressed they would be more likely to participate if they perceived a benefit for their children...*“It will help your children down the road...I think parents aren’t as concerned about themselves as they are their children.”*

Based on this information, Dr. Myers led the development of a facilitator-led educational program that involved small group discussions. As part of the education session, benefits to children were emphasized as an important reason to learn about FHH.

Focus group participants also provided feedback on existing print materials about specific diseases and FHH. They indicated they preferred fact sheets printed in color with large font and photographs of people with whom they could identify. In addition to the six diseases on the Surgeon General’s Tool, the participants also reported wanting to learn about lung cancer, asthma, and depression. As a result of this feedback, Dr. Myers and Dr. Sandy Cornett led the development of nine disease-specific fact sheets and two fact sheets about family health history that met the specifications of the focus group participants (large font, colors, appropriate photographs). The targeted reading level of 7th grade or less was attained with all but two fact sheets. The two fact sheets at higher than a 7th grade reading level were a result of words that couldn’t be changed (such as ovarian in ovarian cancer, family history, etc). All fact sheets were reviewed for reading levels with the FRY Readability Graph. Reading levels of the final fact sheets developed by the Family History Working Group for this project are as follows:

- Asthma - 7.5 grade
- Breast Cancer - 5th grade
- Colon Cancer - 5th grade
- Depression - 7th grade
- Diabetes – 7th grade level
- Family Health History – 7th grade
- Family History is Important to Your Health – 8th grade
- Heart disease - 6th grade
- Lung Cancer - 4th grade
- Ovarian Cancer - 8th grade
- Stroke - 7th grade

Participant Characteristics

Education sessions were held at one of four community organizations with networked computers. A total of 13 Education Session Is and 12 Education Session IIs were held (two Education Session IIs scheduled for the same day at the same facility were combined into one due to a PCO schedule conflict). The number of attendees at an education session ranged from 5 to 13. One hundred women with less than a college education attended one of the first education sessions and 92 returned to the second education session. All 100 completed a FHH (49 on

paper and 51 electronically). Eighty-eight percent of participants indicated they, a parent, or grandparent either self-identified as Appalachian or was born in an Appalachian county. Additional participant characteristics are described in Table 1.

Table 1: Characteristics of Participants Attending Education Session I

	Total (N=100)
Highest Grade	
≤8th grade	17%
Grade 9-11	33%
GED or 12th	38%
Some college	11%
Age	
19-29	36%
30-39	22%
40-49	16%
50-59	16%
60+	9%
Race	
White	79%
Black	18%
Any Children	89%
PCO Site	
Cincinnati, OH*	43%
Dayton, OH**	25%
Newport, KY	32%

* Includes participants recruited through two PCOs in Cincinnati

**Includes participants recruited through three PCOs in Dayton

Satisfaction with Education Sessions

After each education session, participants were asked to indicate how satisfied they were with the location of the session, the length of the session, and the facilitator who led the session. Eighty percent were very satisfied with the length of the first education session, 89% were very satisfied with the location of the first education session, and 93% were very satisfied with the facilitator. After the second education, 79% were very satisfied with the length, 95% were very satisfied with the location, and 98% were very satisfied with the facilitator. With regards to length of the session, the most common complaint was not allowing a cigarette break, and with regards to location, the most common complaint was difficulty gaining access to one facility which had a long flight of stairs.

Although all women were able to complete their family history using “My Family Health Portrait”, not all felt they could find the tool on the internet. Only 67% of participants reported they had enough training to find the Surgeon General’s FHH form on the internet, and only 50% reported they could easily teach a family member to find this form.

Evaluation of fact sheets developed by the Family History Working Group

The 11 fact sheets developed or modified for the project were evaluated by participants prior to or during the second education session. Women were asked to read the fact sheets at home (or in Education Session II if they had not read it at home) and circle words on an evaluation form that matched their impressions of the fact sheets. In general, the participants had positive associations with the fact sheets as noted in Table 2. Experts were also asked to review the content of the fact sheets, and a few modifications were suggested and incorporated into the final fact sheets (Appendix 2).

Table 2: Participant's Impressions of 11 Fact Sheets

Fact Sheet	Total	Informs	Dull	Easy	Useless	About Right	Old Stuff	Clear	Hard to Follow	Helpful	Boring
Family History General	69	43	0	32	1	20	0	41	3	55	1
Family History Important	67	35	1	30	4	14	2	38	1	43	2
Asthma	74	46	0	34	2	17	3	45	2	57	1
Depression	73	46	1	34	1	23	3	38	2	55	1
Stroke	71	45	0	35	1	21	1	42	2	47	1
Diabetes	77	51	0	40	1	24	4	47	1	53	2
Heart Disease	72	48	1	40	2	19	0	50	0	50	1
Lung Cancer	74	50	0	34	0	22	3	41	1	50	0
Breast Cancer	67	41	1	30	1	21	2	44	1	50	0
Ovarian Cancer	73	48	0	36	2	25	1	38	1	50	1
Colorectal Cancer	70	45	0	36	1	20	1	38	2	51	0

Impressions of Education Sessions

Efforts were made to make all participants feel comfortable and at-ease during the education sessions. This was primarily done by establishing rapport, learning names, encouraging and actively listening to discussion. Dr. Myers and usually a graduate student arrived early to set-up; meet participants as they arrived, and help participants complete a demographic intake form. Since a cultural aspect of the community was "oral storytelling", questions and stories shared by participants were encouraged and Dr. Myers "programmed" questions into the presentations. For example, she generally began a presentation by asking participants what "family history" meant to them. This method of engagement was quite

successful and once the stories began, redirection skills often had to be utilized to keep the group focused. Dr. Myers also worked as a team with the representative of the PCO to engage participants and earn their trust. Often the representative from the PCO or Dr. Myers would help generate discussion by sharing stories from their lives or experiences. Having the representative from the PCO was extremely valuable as they were also able to relay stories and concerns specific to their particular community. For example, environmental exposures (pollution from industry) were common concerns at one PCO and the representative from that PCO was able to discuss the history of the program as well as programs that had been initiated to deal with these concerns. Respondents often shared perceived barriers to making lifestyle changes. The participants and members of the Family History Working Group in attendance then would talk about ways to overcome these barriers. For example, during one education session, respondents indicated that a barrier to walking as a form of exercise was fear about safety. As a group we then talked about the possibility of walking in pairs from the PCO to and around the nearby police station as a means to exercise and be safe. Another respondent indicated a barrier to eating healthy was knowledge about *how* to eat healthy and everyone agreed it would be great for the PCO to sponsor a healthy cooking class as well as an exercise class.

As mentioned, a great deal of discussion in the second education session centered on talking to a health care provider. Participants felt comfortable sharing their stories and perspectives as a result of previously established relationships with one another and the representative from the PCO, and because rapport had been established in the previous education session. Many participants reported positive experiences communicating with providers, but an equally large number expressed negative interactions and associations with health care providers. As the sessions progressed, it became clear that there was a lack of trust on the part of participants towards health care providers. Common threads included feeling that health care providers didn't take the time to listen to them, or that health care providers made them feel stupid. Many commented that after the long wait to see the health care provider, they just wanted to get out of the clinic. A few expressed fear of a medical diagnosis or embarrassment about discussing personal problems with health care providers. What was particularly impressive was that participants as a group (not just the facilitators) would help problem solve. Participants would often volunteer to go to a medical visit with another person who needed medical attention but was afraid to go. Also by sharing stories, everyone learned additional methods to address challenges communicating with health care providers. For example, one participant who was afraid to ask questions when she had medical concerns often took her mother with her to medical visits to ask the "hard" questions. These discussions about how to communicate with a health care provider were not an original part of the proposal, but were recommended by the PCOs as a result of the cultural themes of fatalism and powerlessness identified in Section III. 1. It turned out to be a very valuable and needed part of the educational program.

Results of targeting health professionals

No increase in the numbers of people accessing the GEPN "Interpreting Family History" self-paced module was seen from the regions targeted by the health professional mailing. Specifically, the number of unique users accessing this website did not increase during the Family History Demonstration Project compared to the proceeding month or the same month one year ago. Evaluation of the Family Physician's and the March of Dimes online offerings were

beyond the scope of this demonstration project and were not ascertained. There were no requests from health professionals for an in-service about family health history.

Process Evaluation

Regular emails to and meetings with the FHWG were held to provide guidance, address challenges, build rapport, facilitate communications, and report on progress of the Family History Demonstration Project. The FHWG met five times during the course of the project, either in person or via phone. It was through these meetings (and many emails) that content of presentations, fact sheets, and logistics were resolved.

VII. Lessons Learned/Challenges Encountered

The community/academic partnerships established through implementation of the Family History Demonstration Project were strong and were essential to successful completion of the project. A testament to this was the subsequent invitation of Dr. Melanie Myers to attend a strategic planning session for one of the community organizations. Community representatives from PCOs who served on the Family History Working Group were invested in the project and contributed regularly to the process. These three representatives worked with other PCOs to recruit participants to the education sessions. However, participants recruited from a PCO where education sessions were not held had a higher no-show rate and were more likely not to meet the specified Appalachian criteria than participants recruited from PCOs where education sessions were held. Discussions with the Family History Working Group suggest this may have been due to two factors:

1. There may have been less commitment on the part of potential participants to “cross boundaries” to attend an education session at a different PCO.
2. Participants who did attend an education session may have had a stronger relationship with the recruiting representative and therefore felt more comfortable attending and a stronger sense of responsibility to attend.

In hindsight it would have been beneficial to have a member of each PCO serve on the Family History Working Group. This was not done initially because all sites did not have a sufficient number of networked computers to allow up to 10 participants the option of completing their FHH online. In addition, it would have been difficult to facilitate and coordinate schedules of all members on the Family History Working Group. In spite of these challenges, having a member from each PCO on the Family History Working Group would likely have increased communications with and participation from PCOs that did not host education sessions. In addition, it is recommended that future programs hold education sessions at the same PCO from which participants are recruited, even if it means holding smaller sessions to accommodate fewer networked computers.

An unexpected challenge was accommodating the schedules of PCOs. Although it was known that certain facilities would only be available in the evening or on certain days of the week, we did not consider that one facility closed during the summer and therefore would have no participants from which to recruit. We therefore chose to wait and schedule at least two education sessions in the fall when the PCO was able to recruit participants.

Probably the greatest challenge encountered in terms of sustainability of the project was logistics. Set-up for the first education session often took 30 minutes and involved bringing in food, setting up a laptop and projector, and getting materials ready and computers turned on. Collecting copies of family histories required a great deal of coordination, particularly since none of the family histories could be saved directly to CD. Instead they had to be saved to a thumb-drive, copied from the thumb-drive to a CD on the PI's laptop, and then returned to the respective participants. This involved a great deal of time and the PI therefore requested additional members of the Family History Working Group attend Education Session I to help participants complete and save their family histories. Subsequent to completing this project, two of the PCOs obtained new computers that had the capability to save directly to CDs.

Printing family histories was also challenging at times. At least one site did not have a printer set-up for the first two sessions. It was critical to provide a print-out to participants completing family histories electronically in the event they did not have access to another printer and wanted to show their FHH to someone or take it to their health care provider. To accommodate this challenge, the PI printed the family histories at her office after Education Session I and brought them back for participants at Education Session II.

Some of the logistical challenges present in the Family History Demonstration Project may not be present in other community settings. For example, other organizations that want to provide FHH education would not need to copy a participant's family health history or collect as much feedback about the process. They might therefore choose to hold just one education session as opposed to two. However, some of the challenges that were overcome in the Family History Demonstration Project by utilizing more members of the Family History Working Group may be more difficult for other community-based settings who do not have as many resources. We were able to provide additional team members to help participants complete their family histories and save participant's family histories to a CD, but other organizations might not have these resources. Community organizations could address these challenges by limiting the size of the education sessions or requiring more participants to complete their family histories on paper as opposed to electronically. The latter option would also save time as completing a FHH electronically generally took about twice as long as completing it on paper (however time to completion was not systematically recorded). The time saved by using the paper tool could be at the expense of accuracy as our findings suggest that the mean prevalence of affected relatives differed when using the paper vs. electronic tool (see supplemental information).

Challenges with the Paper and Electronic FHH Tool

During implementation of the Family History Demonstration Project, we did encounter some challenges with the electronic tool. For example, after entering the total number of relatives on the "Create Family" screen on the electronic version of "My Family Health Portrait", users had to pass through a screen on each family member to get to the end of the tool. This was particularly challenging when time was running out and participants wanted to print a copy of what they had completed to take with them. It was also challenging when participants inadvertently typed in "20" brothers instead of "2" because the relative could not be "deleted" until passing through a screen on all family members. An additional challenge of using the electronic tool was that participants could not change relationships of family members. For

example, if a participant entered that a relative was a “brother” but it should have been a “half-brother”, she had to delete the relative and re-enter the information. While this may not be particularly challenging for someone who is computer savvy, many of the women who participated in the Family History Demonstration Project were not and this step could take considerable time. More than one participant was disappointed that she could not select a parent for nieces and nephews of half-siblings. Demonstrating the lineage for half-nieces and nephews may not be particularly informative from a clinical point of view, but the few participants who encountered this difficulty felt they were “leaving out” part of their family. Other challenges included not being able to indicate if the participant had children with multiple partners and not always being able to delete relatives (a technical glitch). We also learned that participants did not always list cause of death as an additional disease.

We had some difficulties printing FHHs and quickly appreciated the importance of being able to print out the completed pedigree/chart. Without this print-out, participants could not take their FHH to their provider. Many of the problems we encountered when printing FHHs during the Family History Demonstration Project were resolved in November, 2007 when “My Family Health Portrait” was updated by NHGRI. Problems encountered that were resolved after this upgrade include circles and squares that were often cut off in the middle of a page, not being able to highlight more than one “additional” disease when printing the pedigree, and the chart version not indicating lineage for half-sibling (it is no longer an option to just print the chart with the pedigree). In our experience the chart format cut-off “additional diseases” on the right side of the page when we clicked on “print this report.” We had better luck printing the charts in landscape. An additional challenge was that half-siblings did not appear on the pedigree if the parent (lineage) was not indicated.

The paper tool had a separate set of challenges. The greatest challenge was lack of details and missing information on the paper tool. For example, participants often did not record half-siblings or if a relative was deceased. Age of onset of diseases, cousins, and different fathers of children were rarely recorded. Behaviors and lifestyle choices (such as smoking, diet, or exercise) were also rarely recorded on both the electronic and paper tool. We tried to address these problems by demonstrating how to complete the paper tool during the education session and showing where to record this information on both tools (we suggested behaviors be recorded under “additional diseases” on the electronic tool). However, the FHHs were still often incomplete. When completing the paper tool, participants often recorded health of current partner, even if not the father of her children.

Space on the paper tool was another big challenge. Participants often had large families with many half-siblings. If a “box” was full on the paper form, participants often didn’t know where to put additional family members and may have left them off the form altogether. The lack of detail on the paper tool and uncertainty regarding what to do when “running out of boxes” suggests that the differences in prevalence of affected relatives between the paper and electronic tool may have been related to the format and lack of prompts on the paper tool. However, additional research is needed to determine if other factors account for some of these differences.

VIII. Next Steps

Our ultimate goal was to establish a model demonstration project to teach consumers the importance and use of FHH that can be applied in other communities. To that end, our project was successful and all resources developed for use in the Family History Demonstration Project, including evaluation tools, and similar methods can be utilized in other communities. Our lessons learned can help guide future community organizations interested in offering similar programs.

Next steps identified as a result of the Family History Demonstration Project include identification of factors that influence consumers to seek medical care related to FHH and reasons they choose to complete the electronic versus paper form of “My Family Health Portrait.” An assessment of whether accuracy of information recorded on the paper versus electronic tool differs according to characteristics of consumers (e.g. familiarity with computers or comfort with the medical community) or whether accuracy of information recorded differs according to characteristics of the tool itself (e.g. prompting for information on the electronic tool) is also needed. The above information can then be utilized to modify or improve marketing of the Surgeon General’s Family History Initiative.

Other gaps needing further investigation include learning more about consumer and provider access, acceptance and utilization of FHH information. In other words, are consumers willing to take their FHH to providers? If so, how do providers use this information in practice and does the use of FHH lead to changes in health behavior and medical management and ultimately lead to improved health? This information is particularly critical if evidence-based guidelines related to FHH are to be developed.

Finally, findings from the Family History Demonstration Project suggest education sessions are helpful in teaching consumers about the importance and use of FHH, particularly women with less than a college education. Next steps include expanding education to other populations (e.g. men) and communities to determine if the results presented here are generalizable to other communities. Parallel to expanding education to other communities should be the development of a sustainable FHH education program for all consumers, including those who are under and uninsured. Further partnerships with businesses, libraries or community organizations to develop an independent, multi-media training about FHH would reach more consumers and perhaps be more sustainable than in-person trainings about FHH.

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9. Information about east side Dayton neighborhoods that are predominantly urban Appalachian (Springfield, Burkhardt, and Historic Inner East) was provided by Dr. Carol Baugh and the Southeast Dayton Weed and Seed.

X. Supplemental Information

Additional Project Results and Evaluation

[Table: Characteristics of Participants by PCO Attending Education Session I](#)

[Figure: Important Reasons to Collect FHH](#)

[Table: Intended Use of Family Health History and Tool Used](#)

[Table: Mean Prevalence of Affected First and Second Degree Relatives \(n=92\)](#)

[Table: Location of Education Session and Tool Used](#)

Supplemental information for this report is currently in press. If you would like more information before publications are made available, please contact Melanie Myers.