

**Developing a family health history educational program for urban Appalachian women: focus group findings**

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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, no low literacy resources were identified. Our long-term goal is to develop a model program that educates individuals with low literacy skills about the collection and use of their FHH. As the first step, we held two focus groups with urban Appalachian women in Cincinnati and Dayton, OH who had less than a college education. Our goals were to understand how this group defined FHH, what they perceived the importance of FHH to be, and how they would like to learn about FHH. We partnered with six community organizations providing services to urban Appalachians in the target areas. The focus groups were audiotaped, transcribed, and summarized according to the goals of the project. Twenty-four women (12 in each focus group) between the ages of 20 and 64 participated. Five participants had some high school, ten had a GED or high school diploma, and eight had attended some college. The majority (n=16) self-identified as white or "Appalachian," four were black, three were part Cherokee, and one reported "other." When asked, most defined FHH as the health or illnesses that reoccur in the family bloodline. All participants felt the importance of knowing FHH was to understand what illnesses may be passed down from one generation to the next. Finally, when developing a format for a FHH educational program, participants recommended an interactive discussion group led by a facilitator and stressed they would be more likely to participate if they perceived a benefit for their children. An educational program that involves small group discussions about FHH and focuses on benefits to children may be well received by urban Appalachian women and other communities with low literacy skills.

Key words: family history, Appalachian, low literacy, community

# Developing a Family Health History Educational Program for Urban Appalachian Women: Focus Group Findings

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## BACKGROUND

➤ Family health history (FHH) is promoted as a tool to improve health and prevent disease. Although FHH tools, such as the Surgeon General's "My Family Health Portrait,"<sup>1</sup> and resources about the importance of FHH exist, we did not identify any low literacy resources about FHH.

## OBJECTIVES

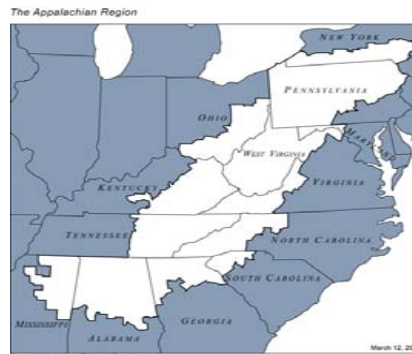
➤ To develop a model program consistent with the US Surgeon General's Family Health Initiative that educates individuals with low literacy skills about the importance of FHH, we wanted to learn:

1. How urban Appalachian women defined FHH
2. What they perceived the importance of FHH to be
3. How participants would like to learn about FHH.

## METHODS

- Urban Appalachian women with less than a college education were recruited to participate through local community organizations.
- Appalachian heritage was determined if a participant, her parent, or grandparent self-identified as Appalachian or was born in an Appalachian county as designated by the Appalachian Regional Commission (Figure 1).
- Two focus groups were held--one in Dayton, Ohio, and one in Cincinnati, Ohio. Each focus group lasted two hours. Focus groups were audiotaped, transcribed, and summarized.
- A professional moderator led the focus groups with a discussion guide that included questions consistent with our objectives.
- All participants were reimbursed \$25.

Figure 1.



## RESULTS

➤ Twenty-four women (12 in each focus group) between the ages of 20 and 64 participated. Participant characteristics are described in Table 1.

Table 1.

Education Level:	Dayton	Cincinnati
No HS diploma	1	4
GED or HS diploma	3	7
Some college	7	1
<b>Age:</b>		
20-29	2	5
30-39	3	3
40-49	2	2
50-59	4	2
Over 60	1	0
<b>Race:</b>		
White	9	10
Black	2	2
Other (not specified)	1	0
<b>Number Of Children</b>		
0	4	1
1-3	5	7
4+	3	4

➤ When asked, most defined FHH as the health or illnesses that reoccur in the family bloodline.

*"Illnesses that reoccur in your family line. Like hypertension, diabetes, heart trouble."*

*"If they are not blood, then your health is not mixed in with them"*

➤ Participants felt the importance of knowing FHH was to understand what illnesses may be passed down from one generation to the next. They recognized the need to be aware of FHH so they can take action or recognize the illness in a family member.

*"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."*

*"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 and stressed they would be more likely to participate if they perceived a benefit for their children.

*"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."*

*"This is a comfortable way to talk about this. I learned more here than I do in class."*

*"It will help your children down the road...I think parents aren't as concerned about themselves as they are their children."*

## DISCUSSION

➤ An educational program that involves small group discussions about FHH and focuses on benefits to children may be well received by urban Appalachian women and other communities with low literacy skills. Subsequent to these focus groups, we held educational sessions with small groups of urban Appalachian women to educate them about the importance of family health history for themselves and their children.

## REFERENCES

1. "U.S. Surgeon General's Family History Initiative." 15 Nov. 2006. U.S. Department of Health and Human Services. 26 Sept. 2007 <<http://www.hhs.gov/familyhistory>>.
2. "Appalachian Region." Appalachian Regional Commission. 26 Sept. 2007 <<http://www.arc.gov/index.do?nodeId=2>>.

**Family History Demonstration Project among Urban Appalachian Women  
Presented at CDC 10<sup>th</sup> Anniversary of Public Health Genomics Meeting, Atlanta,  
GA, January 23, 2008**

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**Background:** Family health history (FHH) is promoted to the general public as a genomics tool to improve health and prevent disease. Although FHH tools and resources regarding the importance of FHH exist, few resources target individuals with low literacy skills.

**Methods:** We partnered with six community organizations to develop a model program to educate urban Appalachian women with less than a college education about the collection and use of their FHH. Participating community organizations invited eligible women of Appalachian heritage to participate in two education sessions (spaced two weeks apart) about FHH. Our objectives by the end of the first education session were for all participants to 1) record their FHH using the Surgeon General's "My Family Health Portrait," 2) identify the importance of FHH in promoting health and preventing disease, 3) explain how to access "My Family Health Portrait" using the internet, and 4) identify at least four relevant questions to ask relatives to collect their FHH.

**Results:** A total of 100 eligible women between the ages of 19 and 70 attended one of 12 of the first education sessions. Fifty-one participants had less than a 12<sup>th</sup> grade education, 37 had a 12<sup>th</sup> grade education or GED, and 11 had attended some college. Most participants (90%) had children, and 78% self-identified as white while 18% identified as black.

Approximately half of the participants chose to record their FHH using the paper version of "My Family Health Portrait" and half chose the electronic version. All participants were able to identify reasons they felt it important to collect their FHH. The most common reasons were to "learn about health problems that run in my family" (96%) and "to pass information on to my children" (91%). Sixty-three percent of the participants felt they had enough training to find the Surgeon General's FHH form on the internet. Nearly all participants (95%) were able to identify at least four relevant questions to ask relatives about their FHH.

**Discussion:** After attending one education session, urban Appalachian women with less than a college degree were able to successfully complete their family health histories using "My Family Health Portrait." However, only 63% of participants felt they could find the Surgeon General's FHH form on the internet, suggesting access to the FHH tool may be a barrier for women with low literacy skills.

**Key words:** family history, Appalachian, low literacy, community, My Family Health Portrait

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## BACKGROUND

Family health history (FHH) is promoted as a genomics tool to improve health and prevent disease. Few FHH resources target individuals with low literacy skills. We partnered with six community organizations in three cities to educate urban Appalachian women without a college degree about the collection and use of their FHH.

## METHODS

- Focus groups with the target community informed the development of the education program
- Community organizations invited women of Appalachian heritage<sup>1</sup> to participate in a FHH education session
- After a presentation about the importance of FHH, participants recorded their FHH electronically or on paper using the Surgeon General's "My Family Health Portrait"
- Evaluation at the end of the education session determined if participants could:
  - Identify the importance of FHH in promoting health and preventing disease
  - Explain how to access "My Family Health Portrait" using the internet
  - Identify at least four relevant questions to ask relatives to collect their FHH

Figure 1.

The Appalachian Region



## RESULTS

- A total of 100 women attended one of 12 education sessions

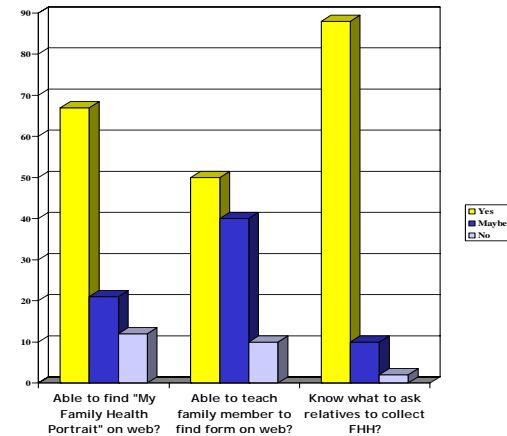
Table 1: Participant characteristics

Highest Grade Completed	Total (N=100)
≤ 11th grade	50%
Grade 12 or GED	38%
Some college	11%
<b>Age in years:</b>	
19-29	36%
30-39	22%
40-49	16%
50-59	16%
≥ 60	9%
<b>Race:</b>	
White	79%
Black	18%
<b>Number of Children:</b>	
0	11%
1-3	65%
4+	24%
<b>Community Organization Site</b>	
Cincinnati, OH*	43%
Dayton, OH**	25%
Newport, KY	32%

\*Participants recruited through two community organizations  
 \*\*Participants recruited through three community organizations

- 51 participants completed "My Family Health Portrait" electronically and 49 on paper
- All participants identified reasons they felt it important to collect their FHH. The most common were:
  - "to learn about health problems that run in my family" (97%)
  - "to pass information on to my children" (92%).

Figure 2. Perceived ability to access tool and ask questions



- More women who completed their FHH electronically felt they could easily teach a relative to find the form than those who completed their FHH on paper (64% vs. 35%, p<.01)
- 95% of participants identified at least four relevant FHH questions to ask relatives. The most common were:
  - "Have any of our blood relatives had any major health problems?" (97%)
  - "How old was our blood relative when she or he developed health problems?" (95%)
  - "Did any of our blood relatives smoke or drink alcohol?" (94%)

## DISCUSSION

After attending an education session, urban Appalachian women without a college degree could:

- Complete their FHH using "My Family Health Portrait"
- Identify the importance of FHH in promoting health and preventing disease
- Identify relevant questions to ask their relatives about FHH

However, difficulty accessing the Surgeon General's FHH form on the internet may be a barrier for women with low literacy skills.

<sup>1</sup> Appalachian heritage: a participant, her parent, or grandparent self-identified as Appalachian or born in an Appalachian county designated by the Appalachian Regional Commission (Figure 1)