

Focus Group Evaluation of Customized Family Health History Education Materials in A North Carolina Community

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ABSTRACT

Background: *The Does It Run In The Family?* booklets provide educational materials about family health history (FHH) and basic genetics to readers of all levels and are customizable for local communities. **Purpose:** The booklets were customized and provided to focus groups to evaluate their usefulness in conveying health information at a low reading level. **Methods:** Three focus groups with 19 participants reviewed the booklets. A semi-structured focus group guide was used. Transcripts were analyzed manually and coded for themes. **Results:** Five themes emerged across all three focus groups: appearance, organization, content, length, and reading comprehension of the booklets. Many participants noted that the booklets were attractive, well organized, contained useful information and were understandable. Participants indicated that the customized materials were interesting. Concerns were expressed about the booklets' length and lack of detailed information. **Discussion:** The focus groups revealed that literacy level, personalization of educational materials, the use of relevant pictures to emphasize topics, phrasing of the title and sentences, and the organization of information are important factors to consider when producing effective community education materials. **Translation to Health Education Practice:** The booklets are distributed through local health organizations to assist community members when obtaining FHH.

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BACKGROUND

Personalized medicine uses family health history (FHH) and genetic testing to improve patient health outcomes. This requires patients to gather family history information so that their risk for various diseases can be adequately assessed. The success of personalized medicine will therefore depend upon the development of effective health education materials about gathering such information.

The development of health educational materials is a complex endeavor involving considerations of target audience, reading level, design and other factors that influ-

ence the quality and usage of the resources.¹ A critical component of the development process is the evaluation of the materials by potential users.

Health Literacy

The Institute of Medicine defines health literacy as "the degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions."² The American Medical Association provides more specific language with its definition: "a constellation of skills, including the ability to perform basic reading and numerical tasks required to function in the

health care environment."³ Therefore, educational materials need to communicate com-

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plex information at a basic reading level.

To facilitate health literacy, health educators suggest that educational materials be written at a 6th-8th grade reading level.⁴⁻⁶ However, creating materials at this grade level may not be enough, as some populations may still be unable to read materials written at this level.⁷ Currently, ninety million adults in the United States have fair to poor literacy, suggesting that a significant portion of U.S. adults are unable to make informed health decisions⁸ even before considering the possibility that even individuals with average literacy might have low health literacy.² Low health literacy is associated with a constellation of factors. These include: living in the South, low cognitive ability, being a member of certain racial/ethnic groups (African Americans, American Indians/Alaska Natives, and Hispanics), advanced age, incarceration and low socioeconomic status.^{2,9}

FHH acts as the bridge between health and genetics. Collecting FHH is essential for the success of personalized medicine. It can also be used as a way to increase health literacy by encouraging patients to learn more about how their health and family history can affect their personal disease risk. Therefore, there is a need to develop educational materials that are useful for low health literacy audiences.

Community Centered Family Health History (CCFHH) Project

The CCFHH project was completed in May 2010. Its intent was to promote conversations about personal health within families in diverse communities through the use of FHH educational materials. The goal of the CCFHH project was to translate conversations about FHH into healthy lifestyle choices and increase community involvement in health education. The aim was that these behavior changes would increase individuals' ability to: (1) be stewards of their own wellbeing, (2) participate in their care, and (3) be full partners in the management of their own health. To accomplish this, it was crucial that the FHH materials were understandable to readers at all levels.

The CCFHH project consisted of two

tiers. Tier 1 involved the development, piloting and evaluation of FHH educational resources by eight partner organizations,¹⁰ followed by the development of an online tool that allows the customization of the FHH educational materials. In Tier 2, 10 organizations were selected to beta test the online tool and disseminate the customized educational resources to diverse communities. The Genomedical Connection (TGC) was one of the selected organizations. Because TGC intended to use the booklets for a community-based education program, it was decided that community focus groups would provide feedback concerning the suitability of the materials for the program. There was particular interest in assessing the utility of the booklets for individuals with low-literacy skills.

PURPOSE

Focus group participants included residents of Guilford County, NC with average and low-literacy skills. This report describes the development of the CCFHH educational materials and the results of the booklets' focus group evaluation. TGC is a multi-staged demonstration project aimed at developing a clinical systems model, centered on the use of FHH, which incorporates personalized medicine into primary care.¹¹⁻¹²

METHODS

Instrumentation

The CCFHH project created customizable educational materials in an effort to be relevant in diverse communities. The educational materials originated from the *Healthy Choices through Family Health History Awareness* (Healthy Choices) project and served as the basis for the *Does It Run In The Family?* toolkit, which included two customizable booklets.¹³

The first booklet (Book 1), *A Guide to Family Health History*, explains the importance of family health history, how to collect it, and how to organize it (Figure 1). The U.S. Surgeon General's *My Family Health Portrait* was referenced as a way to easily collect and organize FHH.¹⁴ Organizations used photos, personal health stories and local or com-

munity resources to customize the booklet for their organizations.

The second booklet (Book 2), *A Guide for Understanding Genetics and Health*, provides a basic overview of genetics and information on genetic links to common health conditions, such as heart disease, diabetes and cancer (Figure 2). Each organization customized the booklet with information on particular conditions that are common or relevant to target readers (for example, National Psoriasis Foundation included information on psoriasis).

The booklets were modified for the CCFHH project with input from American Folklife Center at the Library of Congress (Book 1), the American Society of Human Genetics (ASHG) (Book 2), and all eight tier-one community partners. All partners provided feedback for booklet modification during an initial project meeting followed by conference calls and an extensive email exchange with drafts and revisions.

After feedback was collected, Book 1 was modified by: (1) minimizing the size of the booklet from 8.5" x 11" to 5.5" x 8.5", (2) increasing space for stories and pictures, and (3) increasing the page count from 16 to 24 pages. The size of the booklet was reduced so that it would be the same size as Book 2 to create a matching set. To accommodate both decreased booklet size and increased space for stories, the number of pages was increased. Book 1 was further modified by reorganizing so it is broken down into sections on collecting and organizing FHH information and increasing the focus on the *My Family Health Portrait*.¹⁴ The aim was to convey clearly why family health history is important and how to collect and store FHH information; *My Family Health Portrait* offers a simple way to keep track of the information if individuals do not want to write or draw it out themselves.¹⁴

Simultaneously, Book 2 was modified by: (1) increasing the narrative text, (2) adding simple section headings to reflect questions that individuals may ask themselves when using the first booklet, (3) decreasing the scientific content, (4) allowing for organizations to customize conditions at the end



of the booklet, and (5) adding a "Hints for Health" section for each condition to give readers take-away action items. All these changes were designed to make the booklet more accessible and intuitive. Decreasing scientific content helped lower the reading level of the booklet, while retaining important information about basic genetics and inheritance. The opportunity to customize the booklets as to which conditions were included enabled partners to create materials that were relevant to their constituencies rather than trying to implement a one-size-fits-all resource in diverse communities. Finally, both booklets were modified to increase use of first person pronouns (i.e. me, my) so that readers would more readily identify with the content.

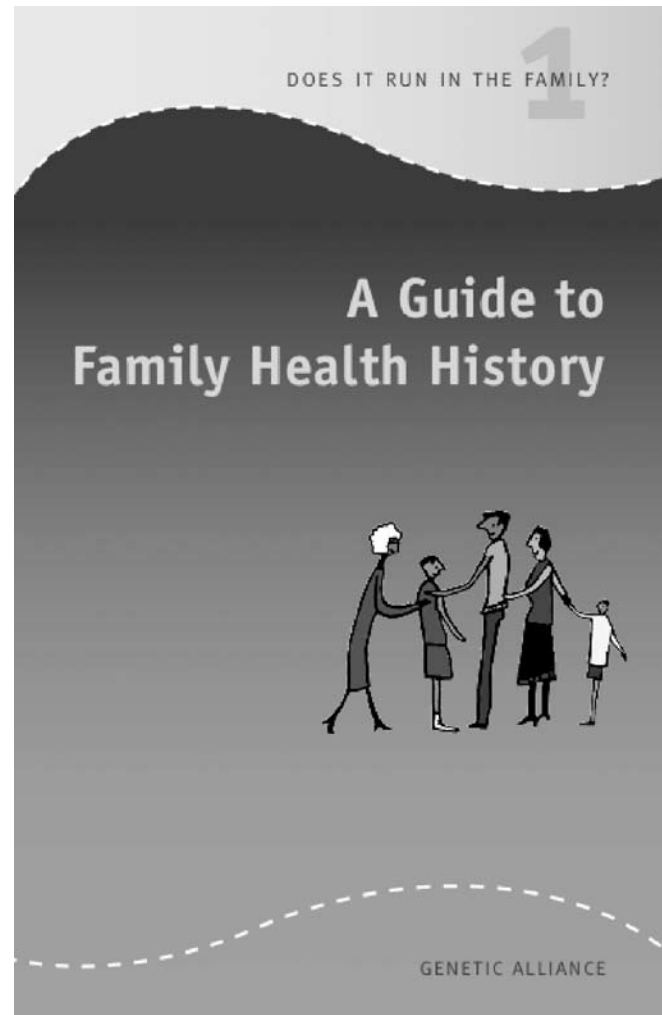
The modified booklets were piloted in 2007-08 with seven of the eight tier-one CCFHH partner organizations. Both tier-one and tier-two partners customized the booklets for their communities and provided comments and edits that were incorporated into the new template versions. The reading level of the booklets was reduced by using short sentences and when possible, words of three syllables or less, to a grade level ranging from 6.7 to 7.5 using the Fry Readability Score.

Through a cooperative agreement (U33MC06836) from the Genetic Services Branch of the Maternal and Child Health Bureau, Health Resources and Services Administration (HRSA), Department of Health and Human Services, an online version of the *Does It Run In the Family?* toolkit was created that allows individuals and organizations to customize the CCFHH educational booklets. The customizable tool and the template versions of Books 1 and 2 are available on-line.¹⁵⁻¹⁶

TGC submitted real-life personal health stories, information on common diseases including heart disease, diabetes and cancers, support group information for specific genetic conditions, and a list of local resources to the CCFHH staff. A section on single gene disorders in the Book 2 template was replaced with a discussion about the familial nature of disease to help people appreciate

Figure 1. Book 1 in the *Does It Run In the Family?* toolkit, *A Guide to Family Health History*

This booklet provides information to help families collect, organize and understand their family health history. It can be customized with personal stories, photographs, quotes, interview questions and resources.



the multifactorial nature of disease. Information about Mental Illness was also added because there is little information on the familial nature of this disease. The customized booklets were printed and incorporated into a community education initiative.

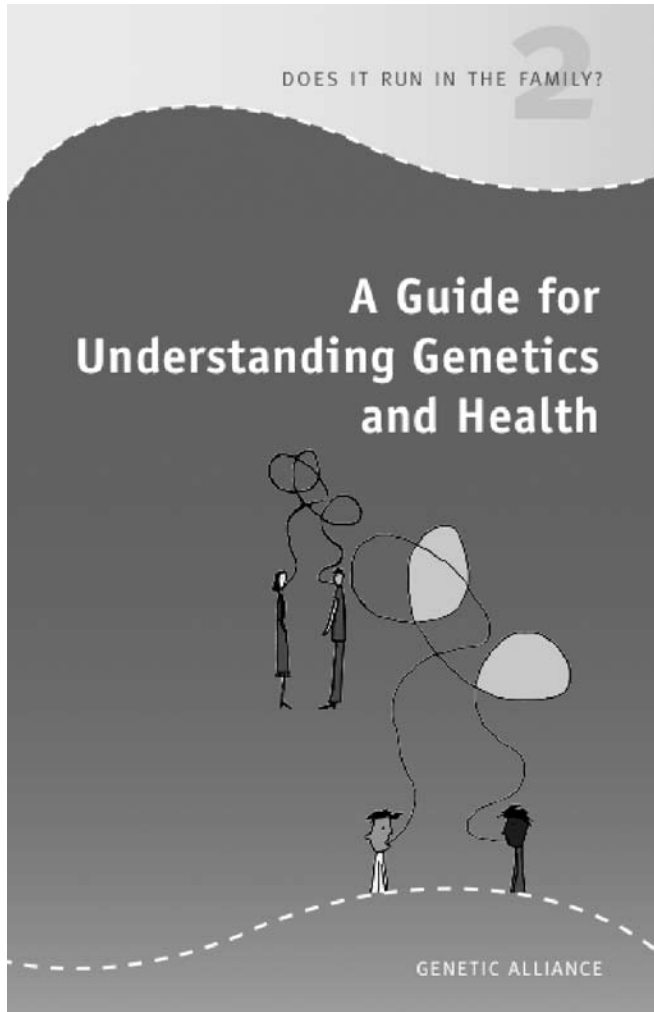
As part of this education initiative, focus groups were conducted to assess the community's comprehension of the information included in the booklets as well as the attractiveness, usability, and persuasiveness

of these materials. To do this, an open ended, semi-structured interview guide was created by genetic counselors, researchers and health educators (Table 1). The questions were based on a review of the literature regarding the creation of low literacy materials.¹⁷⁻¹⁸ For two questions, the guide instructed participants to write down their thoughts about key issues and instructed the facilitator to ask each person what they wrote (Table 1).

Congregational nurses, nurses employed

Figure 2. Book 2 in the *Does It Run In the Family?* toolkit, *A Guide for Understanding Genetics and Health*

This booklet explains the basics of how genetics impacts health and how knowledge of family health history can be used to help individuals stay healthy. It also describes multiple diseases that “run in the family,” who is at risk and hints for health. It can be customized with disease-specific information and resources.



by churches or other faith communities, and instructors at the local community college were used as key contacts to identify individuals to participate in the focus groups. Subjects were recruited through the key contacts using IRB-approved statements, flyers, or word of mouth among organization members. Members of one church and students enrolled in a remedial reading class at the community college agreed to participate in the review of the *Does It Run In the*

Family? booklets (Table 2).

The facilitator was assisted by a note-taker who distributed consent letters, a demographic sheet and the booklets to be reviewed, managed the recording device and took field notes. Three focus groups of six to seven individuals each were conducted with a convenience sample of 19 total participants during March and April, 2009 in Guilford County, NC (Table 2). No identifying information was collected from the participants.

Focus groups were held in classrooms of a local community college or meeting rooms of local churches. All sites were set up with chairs around the tables, and participants were provided paper and pens to write down their answers when necessary. As noted in Table 1, focus group participants were asked to write down and read their thoughts and the key points of the booklets. Focus groups lasted for approximately 90 minutes and were audiotaped with the permission of the participants. Each participant received a \$20 gift card to a local grocery store as compensation for his or her time.

Audiotapes were transcribed verbatim, and the transcripts were reviewed for accuracy against the audiotape and field notes taken for each session. Analysis of data included long-table methodology as described by Krueger and Casey.¹⁹ Each statement within the transcribed data was first individually coded by topic area. This allowed the investigators to not only analyze each statement in isolation but also be aware of where the statements occurred throughout the focus groups. All coded statements were then grouped according to consistent themes. Reliability and validity measures were applied in the focus group research. This included using: a focus group interview guide; one facilitator for all focus groups; an audiotape to record the focus groups, from which the written transcripts were made in full and used for the analysis; and a note-taker during the focus groups to document the focus groups and write down observations.¹⁹

The methodology for the focus groups was approved by The University of North Carolina at Greensboro and the U.S. Army and Materiel Command Institutional Review Boards.

RESULTS

Focus Group Demographics

The demographics of each group can be found in Table 3. Individuals participating in focus group 3 were part of a remedial reading course at a local community college and included non-native English speakers. Overall, participants were 67% ($N = 12$)



male, 56% ($N = 11$) non-Hispanic white, 17% ($N = 3$) black or African American, 17% ($N = 3$) American Indian or Native Alaskan, and 6% ($N = 1$) Asian. The educational attainment of the participants was: 11.1% ($N = 2$) Did not graduate from High School; 22.2% ($N = 4$) Graduated from High School or GED; 16.7% ($N = 3$) College 1-3 years (some college or technical school); 27.8% ($N = 5$) Bachelor's degree; 16.7% Some Graduate School; and 5.6% ($N = 1$) Master's Degree. This is similar to the county's educational attainment where 13.8% did not graduate from High School, 26.8% High School Graduate or GED, 20.6% Some College, 21.9% College graduate, and 10.2% Graduate or Professional degree.²⁰ The focus group population represents an oversampling of males and undersampling of non-Hispanic Whites compared to the Guilford County community, whose demographics are: 45% male, 65% non-Hispanic Whites, 32% African American, 5% Hispanic, and 1% Asian.²⁰ Ages of the participants ranged from 20-71.

Themes emerging from the focus groups were organized into five main categories based on the booklets' appearance, organization, content, length and comprehension. Responses were similar across the focus groups. Selected passages are given for each theme.

Appearance

The appearance of the booklets was discussed in response to almost every question that was asked. The most common topics were the color of the booklets and the graphics. Members of all groups agreed that educational materials need to "grab your eye," but there was disagreement on how this should be done. All agreed that the color of the booklet is important as it can set the tone for the booklet, making it "comforting" or "scary". For instance, an individual in one group said, "Blue would really be great. It's comforting." However, people also commented on actual booklet colors: "...red [the color of the Book 2 cover] is associated with...bad things, so it's...a scary color..." though another said that red made it stand out so that "...if it were sitting on

Table 1. Semi-structured Interview Guide

1. How many of you have picked up a brochure of any kind in the past three months?
 - a. Do you ever pick up brochures?
 - b. When?
2. When thinking about those brochures, can you remember what your reason was for picking up the brochure?
3. What are you looking for when you pick up a brochure?
4. How would you define a good brochure?
5. When you look at the cover of this brochure, write down the first thing that comes to mind. *(Go around the room and have people read off the thoughts that they wrote down.)*
 - a. What is it that you think makes you feel/think that way?
6. Does the cover give you an indication of what you might find inside?
7. Would you pick up this brochure if you saw it in your doctors' office?
 - a. Why?
 - b. Why not?
8. Please take a minute and read through the brochure. In your own words write down what you think are the key points. *(Go around the room and have people read off what they feel their key points are.)*
9. What do you like about this brochure?
10. What don't you like about this brochure?
11. Is there other information you would include?
12. What do you think about the reading level?
 - a. Is it too low?
 - b. Too high?

Table 2. Focus Group Participants

Community Organization	Number of focus groups	Total number of participants
Presbyterian Church		
Men's group	1	7
Young People's group	1	6
Community College class	1	6
Total	3	19

Table 3. Individual Focus Group Demographics

Focus group	Average age	Race	Hispanic	Year of School	Male:Female
1	29.2 years	5 White 1 American Indian	0 Hispanic: 6 Non-Hispanic	2 College 1-3 years 2 Bachelor's degree 2 Some graduate school	1 M:5 F
2	64.1 years	5 White 2 American Indian	0 Hispanic: 7 Non-Hispanic	1 High School graduate or GED 1 College 1-3 years 3 Bachelor's degree 1 Some graduate school 1 Master's degree	7 M:0 F
3 ^a	26 years	1 White 3 Black 1 Asian	0 Hispanic: 5 Non-Hispanic	2 Some high school/did not graduate 3 High School graduate or GED	4 M:1 F

^a One participant did not complete the demographic sheet. Information is based upon forms that were completed.

a shelf...I would be more apt to pick it up." The green/yellow color scheme for Book 1 also was noted: "I really like the colors. I like green. I feel like it's bright enough to kind of catch your eyes, the green and yellow next to each other."

Focus group members also remarked on the graphics within the booklets, including title, pictures, font and decorative work on the pages. All groups commented on the title and pictures. One participant mentioned that the title of the toolkit, *Does it Run in the Family?*, was important to make the booklet meaningful to him. "The question on here... is that a question I have?" An individual in an average reading level group commented that s/he did not like the title of Book 2 (*A Guide for Understanding Genetics and Health*). This individual stated, "I would probably be turned off by that...because it seems like...scientist language." Other individuals in this same group stated, "I think that [it] would keep people from picking it up" and "genetics scares people." Others commented on the titles and pictures on the front covers and the importance of these relating to each other. For example, Book 1 is titled *A Guide to Family Health History* and has a picture of a family on the cover (Figure 1). Some

participants in each group felt that this picture related to the title. In contrast, Book 2 is titled *A Guide for Understanding Genetics and Health*, and the cover illustration shows two couples. Between each couple a line is drawn from one individual's mouth that circles above the couple's heads and comes down to the other person's mouth to indicate discussion or communication (Figure 2). Participants in an average reading level group and the lower reading level group thought that this looked like the couples are smoking, rather than communicating about genetics and health. One person in the lower reading group simply stated that he did not "...understand what the picture means." Some participants in all groups liked the cartoon style of the pictures in the booklet. A participant said, "I really like the drawing, because it's kind of cute. It's kind of cartoony, and it makes it look approachable." Nevertheless, one participant stated, "As I started flipping through [the booklets] the cartoons started to distract me." Another mentioned that the "cartoons did not help with getting the points across."

Participants from each group commented on the font and decorative work on the front cover and throughout the booklets.

All comments recorded about the font size and text color were positive. One person reflected on both books, "The bright red, large print draws you into that one concept," while another remarked about both books, "The font size is a nice size; not too big, but not too small." Individuals in each group also liked the bold font used to highlight specific topics such as "How do I collect family health history?" or "Diseases that run in the family." One person said, "Looking at a page you could tell what it was going to talk about." One group commented on some of the decorative work in the booklets. A participant noted, "I liked the curves in it...it focuses you but lets you ramble too."

Organization

The table of contents page of each booklet was specifically noted in the two groups of average readers. A participant in focus group 1 declared, "I loved the fact that it had a contents [page], because a lot of pamphlets don't...This gives you an idea of what you're getting." Another in this same group further noted: "If you don't want to read the whole thing, you can choose what you want to read." A participant in another focus group stated, "...I like the way it's set up. The Table of Contents gives you a lot of information."



The table of contents in Book 2 was dissimilar to the table of contents in Book 1, and according to individuals in Focus Group 1, less organized. While Book 1 was organized by topic (e.g., Collect [family health history], Organize [family health history], Understand [family health history]), Book 2 was organized by questions (e.g., Why is genetics important to my family and me?, What makes me unique?, Why do some diseases run in families?). Participants in focus groups 1 and 2 preferred the topical organization to the questions. Other organizational details were also noted, including the transition and flow between topics in both books ("The way that it is organized, very sequential, logical, very logical."). Individuals in the lower reading level group did not comment on the table of contents.

Content

Individuals in every group discussed the content when asked what they liked about the booklets. Specifically, several participants mentioned that they liked the detailed information on how to collect family health history (Book 1), the preventative focus of the booklets (Books 1 and 2), and how the wording made the booklets seem more personal (Books 1 and 2).

All groups commented on the section about collecting family health history and the questions to ask family members. "I liked...all the suggestions in here about how to collect family information. I thought it had great ideas on how to get together with people. Because when you get together with your family sometimes you don't know what to talk about with them." The participants also liked the "step-by-step" instructions in Book 1 on how to collect family health histories.

Participants in all three groups remarked on the prevention messages of both booklets. When asked what they thought was the key point of the booklets, one participant said "preventing illness by knowing your family health history and making a good choice." Another person commented, "I...liked...where it says 'Remember, share your family health history with your doctor. Ask if you can be screened for a disease that runs

in your family.' I felt like that was trying to empower the individual." Several participants commented on the text's suggestion to record family history and pass it on to future generations. Another section, "Hints for Health," in Book 2 was mentioned by individuals in all groups because it provided information on how to remain healthy, even when at risk for getting a disease. One person stated, "it can be a little scary...Oh, my God that could be me. Oh, wait, I can do something also." Another participant stated, "...it also goes on to tell you even if you are doomed...what you can do to reduce the severity."

There were many comments about the phrasing of the booklets and how they made the subject more personal for the reader. Two groups specifically mentioned the real-life stories in Book 1. One person revealed that they liked "the little pictures with the story." Another participant specifically noted the young age of the woman who got breast cancer, saying "...at 33, that's not too far down there." Individuals remarked about the first person language used in the headings, such as, "What makes me unique? Tell me more about my genes." One person commented that the wording "made it personal. I like that factor because...it really brings you into the book...and makes you relate to it."

Participants in an average reading level group and the lower reading level group felt more information was needed in some portions of the booklets. One person asked, "How can knowing my family health history help me stay healthy?...the only thing on this page that answers that question is... 'Understanding how healthy life choices can help lower your risk for getting a disease.'... That doesn't give me any information on how to stay healthy." The lower reading level group felt that the information could be worded more strongly and more details should be added so that "...people will understand more about it." Similarly, one group appreciated the sections that provide resources for more information and contacts for local support groups for the diseases mentioned in Book 2. However, they also mentioned wanting more resources put into the booklets.

Length

The booklets' length was noted as a concern by two groups. Participants indicated that readers of all ages, but specifically younger readers, would not read the entire booklet. One person indicated, "The battle that you have is that the generation after ours wants the answers right out there so they don't have to look too hard. ...[T]hey want to be able to push a button and have it flash on the screen instead of reading a whole book to find it." Another participant in the same group stated, "[I]'ll look a little bit harder [for information]...but not much." Participants from another group said, "I wouldn't read it. It's too long. It's too much," and "To an extent it's kind of thick. So you could make some of it more concise without having all of the doodads [cartoons] everywhere, I think it would be a little bit nicer to some of the younger people who are like, 'I don't have time to read that much.'" A participant specifically commented that s/he felt Book 2 was "really wordy."

Comprehension

Members from all groups felt that the booklets were easy to read. When asked the question "What do you think about the reading level? Is it too high? Too low?" the responses ranged from "It's good," "Completely understood," and "It's all right" to "standard brochure reading level" and "very simple, and no big words in here." In spite of these comments, two misunderstandings were revealed through the discussion in the lower reading level group. One person confused the word "affect" (e.g., How can my choices affect my health?) for affection. Other participants in the same group became confused when reading a sentence that listed factors that can affect a person's health. The sentence contained factors that can positively or negatively affect health (e.g., Other things—such as what you eat, whether you smoke, whether you exercise, and what you do for a living—can be influenced by the choices you make.) This sentence was interpreted to mean that exercising is bad for your health. One person said "...what you eat, or if you smoke, or exercise. This is the part



that I didn't understand. If you exercise, they talk about working out? How is that going to affect our health? I know smoking is bad. Like working out is what?" Participants in two groups commented that Book 2, which contained information about specific diseases, was harder to read—"When you start getting into the diseases it gets little more difficult." However, no misunderstandings were evident in the discussion about the diseases section in Book 2.

DISCUSSION

As part of a community-based personalized medicine initiative, the *Does it Run in the Family?* booklets were tailored to, used and evaluated by one North Carolina community. The goal of these materials is to educate community members reading at a low reading level about multiple topics—the importance of knowing FHH, how to collect FHH, diseases that can run in the family, and local resources—in order to facilitate conversations about health within the family. While each focus group offered several diverse editorial suggestions, no major changes were proposed by participants in any of the groups.

As noted earlier, the development process involved both professional and community input and both books had been lengthened. However, two out of three groups commented that the booklets were too long and that many readers would not read all of their content. Therefore, the length of educational materials for communities requires a balance between length and completeness of information, as other focus group participants indicated that some information was missing.

Low literacy often provokes shame and social stigma in individuals, resulting in many individuals not telling friends, family members or healthcare providers of their reading ability.²¹ Individuals may try to hide their inability to read through several tactics, such as pretending to forget their reading glasses or indicating that they need to talk with a spouse.²² In an attempt to minimize this effect, all focus group members were asked to write down their

thoughts about the key points of the booklets and what the covers of the booklets meant to them.

The focus groups highlighted the desirability of graphics that relate to the intended message, as well as the need for their thoughtful inclusion. Pictures and graphics are important in educational materials as an alternative to text, in order to present relevant information to visual learners.²³ Care must be taken when using pictures to make sure that they match the text so as not to confuse the reader, as was the case with Book 2's cover. Participants also pointed out that the cartoon pictures, while friendly and inviting, can be distracting because of their frequency and complexity.

All groups commented on the organization of the booklets, including how the pictures and graphics relate to the topic of discussion, the table of contents, and the personalization of messages to the reader. Participants in the average reading level groups commented favorably about the table of contents, though this feature was not noted in the lower reading level group.

Word choice is also important when developing educational materials. The words used in a booklet can make participants feel drawn in, or discourage them from picking it up. Specifically, the use of scientific language such as "genetics" can put people off and make them less likely to pick up the material. However, the use of the words "me" (i.e., What makes me unique?) and "my" (i.e., Tell me more about my genes) drew the readers in and made them feel as if the books were talking about them. Having the stories of local residents and local resources customized to the community also seemed to reinforce that feeling.

All groups, regardless of reading level, indicated that the booklets were understandable, had similar "take home" messages, and that the reading level was 'good.' Importantly, average level readers did not indicate that the booklets were talking down to them. All groups were able to discuss the sections they were asked to read, suggesting that these materials will be useful for both low and average level readers to learn about the importance

of—and how to collect—FHH, as well as the inheritance of common diseases.

There were few differences in the responses in each theme between the two reading levels. One difference was that individuals in the lower reading level preferred wording that was more concrete, where they would not have to infer meaning. An example of this was a list of factors that could positively or negatively affect a person's health. A second difference that was noted was that both average reading level groups commented on the table of contents and how they could use that to access the information that they wanted. This is consistent with the literature in that individuals with a low reading level may miss the context of meaning and tend not to think in terms of classes of information or categories.²²

These focus groups provided specific reasons for the booklets' potential positive or negative reception by readers. Earlier, Tier 1 CCFHH partners pilot tested the booklets and obtained quantitative measures of success: 89% of participants found the booklets to be somewhat, very, or extremely useful; 90% of participants wanted to use the booklets in the future with their families; and 87% wanted to use them in the future with healthcare providers.¹⁰ Together, the results of the pilot testing and focus groups allow us to conclude that the booklets can be successfully incorporated into many more diverse communities, especially if they are tailored for those groups.

As a result of the focus groups, the Book 2 title was shortened to *A Guide to Genetics and Health* and both booklets were reevaluated for edits that would help to further lower their reading level prior to reprinting. Despite feedback that the word "genetics" can be off-putting, it was kept in the title of Book 2 to most accurately reflect the booklet's content. Additionally, it was kept with the hope that: (1) people will be interested and curious after reading Book 1 and want to continue to Book 2, and (2) the friendly illustrations and use of the words "me" and "my" will keep them engaged and counter any initial fear of the word "genetics."



Limitations

The limitations of this project include the limited number of focus groups ($N = 3$) held to evaluate the educational materials and the relatively small number of participants ($N = 19$). Additionally, focus group participants were not representative of the Guilford County population.

All groups could discuss the passages they read, so it is unclear if the misunderstandings that occurred in one group were a result of being a low level reader or other factors such as being a non-native English speaker. Low level readers, which can include non-native English speakers, tend to take words literally, read slowly and yet miss the meanings, skip over words that are unfamiliar to them, miss the context of presented information and tire quickly.²³ The booklets discussed genetics, family history and inheritance, which could have been a new or difficult subject for the group. Many cultures do not openly discuss diseases that run in the family because it can be stigmatizing. However, it was beyond the scope of this project to determine if the reason for the misunderstanding was a result of cultural differences, literacy level or both.

TRANSLATION TO HEALTH EDUCATION PRACTICE

Based on recommendations from the focus groups, the educational materials were further edited and are now being distributed through local health organizations to help community members obtain family health history information. Readers are encouraged to compile these results and consult with their providers to determine whether they have a hereditary or familial risk for a variety of diseases and to discuss possible interventions and treatments that could reduce such risks.

Despite efforts to lower the booklets' reading level below the average 8th grade reading level,²⁴ a few participants still misunderstood some material. The focus groups emphasized factors, including literacy level, which should be considered when creating educational materials. These factors include: (1) the use of relevant pictures to relay

messages, (2) organization of the materials, (3) the phrasing of titles and sentences, and (4) customizing the brochure to the elements that are important to the target community. Specifically, participants emphasized the importance of: (1) personalizing the materials (i.e., stating sentences in first person or customizing materials to a specific audience) to draw in readers; (2) creating lists of items with similar characteristics (i.e., separating smoking and exercising); (3) using non-scientific words in the title, specifically avoiding the word "genetics;" (4) a logical organization of topics with a table of contents when applicable; and (5) knowing that readers with average comprehension levels are not put off by literature written at lower levels.

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