



## ABSTRACT

The Guilford Genomic Medicine Initiative (GGMI) is a collaborative demonstration project involving Moses Cone Health System, The University of North Carolina at Greensboro, and the Duke University's Center for Human Genetics and Department of Medicine. The goal of this initiative is to integrate genomic medicine services into a community health system. GGMI is a comprehensive program, which includes clinical operations, research and education components.

One of the primary education targets is the lay community who will be the future consumers of genomic medicine. As part of a front end educational needs assessment, 13 focus groups were conducted to determine what members of the community know, what they want to know, and how they want to learn about genomic medicine. A total of 121 English speaking residents of Guilford County, age 18 and older, representing seven diverse community institutions and organizations participated in these focus groups. Preliminary data suggest the majority of participants 1) are not familiar with the term genomic medicine 2) believe that genomic medicine is an important topic that the public needs to know about; 3) obtain information about health and medical issues from the Internet, their personal doctor, and various types of media; and 4) are most interested in educational messages that pertain to their own health.



## INTRODUCTION

The integration of genomic medicine services into a community health system, will hinge in large part on the public perception, acceptance and utilization of these services. One way to assess public opinion is through the use of focus groups (Litosselli, 2003). According to Condit (2001) focus group studies have provided insights into the "...range of moral concerns that the public holds about genetic technologies" and "... some potentially important differences in attitudes towards, and knowledge about, genetics [within different social categories] that might well affect health-care delivery mechanisms." However, focus group research in genomic medicine is limited (Condit, 2001). For this reason focus groups were conducted in Guilford County to identify major learning objectives for the community education component of the GGMI. The goals include:

- Assessing participants' awareness and knowledge about genomic medicine.
- Determining their interest in this topic.
- Ascertaining how participants obtain health information.
- Identifying the most effective ways to inform people about genomic medicine.

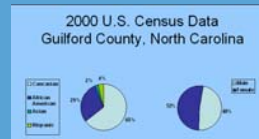
## MATERIALS AND METHODS

- Key material interviews with representatives from the health department and the Chamber of Commerce were used to identify organizations representing a cross section of the community in terms of gender, ethnicity, religion, age and socioeconomic status.
- An open-ended semi-structured script was produced.
- The appropriate institutional review boards approved the study.
- Key persons within each organization were contacted. They were responsible for recruiting participants.
- Focus groups were conducted in the organization's facility and at a time chosen by the organization to ensure maximum participation.
- Focus groups last one hour. A meal was provided and each participant received a \$25 gift certificate at the conclusion.
- Sessions were audio taped and transcribed.
- Content analysis is being done with the assistance of ATLAS TI, a qualitative software package, to identify common ideas, categories and themes. Preliminary data are available.
- Researchers are currently conducting a more extensive analysis of the data to validate the preliminary findings.

## RESULTS

### Demographic Data:

Participants - Institutional Organizations	Number of Focus Groups	Total Number of Participants
Elementary School Teachers	2	14
University Students:		
➤ State School	3	32
➤ Historically Black College	1	16
Church	2	21
VFW Post	1	6
Army National Guard	4	32
<b>Totals</b>	<b>13</b>	<b>121</b>



### The majority of participants-

- ♦ **had not previously heard the term genomic medicine (8 of 13 groups, 62%).**

Most admitted they had no knowledge of the subject. However, when asked what they thought the term meant responses included "genetics," "the genome project," "family history," "using genetics to heal people," and "cloning." Respondents in 10 groups (77%) mentioned hearing and/or being concerned about "cloning," and 9 groups (69%) mentioned "stem cell research."

Participants were more familiar with the term, "**genetic medicine**," and many knew it related to family history, genetics and inheritance (7 of 7 groups, 100%).

Respondents in 5 of 9 groups (55%) mentioned they had heard the term "**personalized medicine**," however, in two instances they reported they did not know what it meant. When asked what they thought the term meant the most common response was that it was a type of medication. "I think it is like your treatment, or your prescription, the way you deal with your illnesses specifically geared toward your body and genetics."

- ♦ **expressed that genomic medicine is an important topic that the public needs to know about (12 of 12 groups, 100%).**

A National Guard member stated, "People are more afraid of what they don't know."

- ♦ **obtained information about health and medical issues from multiple sources including the Internet (13 groups, 100%), their doctor (11 groups, 85%), TV programs and commercials (10 groups, 77%), magazines (7 groups, 54%), newspapers (7 groups, 54%), and the radio (3 groups, 23%).**  
"I have gotten information, limited information; from a doctor and then when I go on the Internet I get the rest of the information. They [doctors] always seem to be in a rush."

- ♦ **are most interested in educational messages that pertain to their own health (13 groups, 100%).**

An NC National Guardsman typified other responses when he said, "my dad has cancer... I don't have cancer, but could I get it? Is that something that I could find out now and head it off at the pass?"

Others noted, "You usually don't think about your health until your health is in crisis or something's going wrong."

"Things that I'm interested in are things that pertain to me..."

- ♦ **offered a number of ways to educate people about genomic medicine.**

The most common responses included the internet, TV, magazines, presentations (7 of 12 groups, 58%), physicians, exhibits (6 groups, 50%), newspaper articles, courses in public schools and universities (5 groups, 42%), pamphlets, billboards, and TV commercials (4 groups, 33%).

Participants again emphasized the importance of making messages targeted and personally applicable (8 of 12 groups, 66%). "I'd say make it personal and related to them because if it's not about them they're not going to care."

They also stressed the importance of keeping the messages simple. "...you really need to simplify things."

## PRELIMINARY CONCLUSIONS

- The majority of participants were not familiar with the term "genomic medicine". Some participants associated genomic medicine with inheritance and family history, and others thought of it in terms of technology. Many had heard the term "genetic medicine" and connected genetics to family history and disease. Few participants were familiar with "personalized medicine" and most often described it as medicines tailored for individuals.
- Most participants noted that genomic medicine was an important topic for people to know about. They reported they are most interested in health information that pertains to them, a family member, or a friend. The majority wanted to learn more about how family history is connected to common diseases such as cancer, heart disease, diabetes, and Alzheimer disease.
- The majority of the participants obtain health information on the Internet. Other common resources included personal physicians, TV programs and commercials. Magazine articles, newspapers and radio were also mentioned.
- A true consensus on the most effective ways to inform the general public about genomic medicine was not evident.

## RECOMMENDATIONS

- Develop educational materials that emphasize the connection between personal family history and the risk of common diseases.
- Create credible Internet resources and informational materials for genomic medicine that use laymen's terminology and are eye-catching.
- Make educational materials, including pamphlets, available to patients waiting for appointments in clinical settings.

## REFERENCES

- Condit, C (2001). "What is 'public opinion' about genetics? Nature Reviews Genetics. 2:811-815.
- Litosselli, Lia, (2003). Using Focus Groups in Research. Continuum Publishing, London.

## ACKNOWLEDGMENTS

This work was performed under the auspices of the "Guilford Genomic Medicine Initiative (GGMI): Margaret Pericak-Vance, Ph.D. (PI), Jeffrey Vance, Ph.D., M.D. Susan Hahn, M.S., Mark Donahue, M.D., Celeste Skinner, Ph.D., William Scott, Ph.D., (Center of Human Genetics and Department of Medicine, Duke University); Vincent Henrich, Ph.D., Karen Powell, M.S., Donna Spoon, B.S., Carol Christianson, M.S., Debra Wallace, Ph.D., Susan Letvak, Ph.D., Louise Ivanov, Ph.D., Ellen Jones, Ph.D., (The University of North Carolina at Greensboro); Pamela Lietz, MBA, Astrid Agbaje, MA (Moses Cone Health System). Thanks to Goldie Byrd, Ph.D. (North Carolina A & T) for serving as a focus group facilitator and to Margaree Parker for serving as a note taker. GGMI is supported by funding from the U. S. Department of the Army (W81XWH-05-1-0383).