

## 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 suggests the majority of participants: 1) have limited knowledge of the use of genetic information in medicine; 2) are concerned about the potential misuse of information; 3) feel there are benefits for people who are susceptible to disease; and 4) would pursue a genetic test or family history evaluation to predict if they were susceptible to disease. A few groups indicated that they would like physicians to initiate the conversation

## 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. After defining the term genomic medicine\*, participants were asked a series of questions about:

- The current use of genetic medicine information,
- What concerns participants have about using genetic information in medicine,
- Whether participants thought there were any benefits to using genetic information in medicine,
- If participants would pursue a genetic evaluation, and
- How they obtained or would like to obtain information.

\* Genomic medicine was defined as "Using an individual's genetic information, such as from genetic testing or family history, to improve a person's healthcare."

## MATERIALS AND METHODS

- Key informant 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 is available.

## RESULTS

### Demographic Data

Participants - Institutions/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>

### Questions and responses:

➢ **What do you know about the current use of genetic information in medicine? (38 responses, 18 respondents (47%) were speaking from personal experience)**

- 13 responses (34%) related to specific uses such as sickle cell screening, preconception counseling, prenatal diagnosis for Down syndrome, sex selection, and specific personal experiences.
- 8 respondents (21%) reported that their doctors collect family history information. However, in two instances they were not sure why. One reported "They always take your family [history], and I don't know the difference it makes in treatment at the beginning stages anyway..."
- 6 responses (16%) related to what they had heard or read regarding insurance and employment discrimination.
- 6 responses (16%) included general observations about the genetics of diabetes and hypertension, the relationship between sickle cell and malaria and the potential for gene therapy.
- 5 respondents (13%) talked specifically about conditions that "ran" in their families  
*"... I only hear that because his mother had it [diabetes] he was more susceptible than his sister would be. His sisters don't have it. But the boys had it..."*  
*"The women in our family have it."*

➢ **What are your concerns about using genetics in medicine? (161 responses)**

- 69 responses (43%) expressed concern about the potential misuse of genomic medicine, the potential side effects, and distrust in the doctors, scientists and the government.  
*"I would be afraid it would be misused"* "Take the wrong thing out, all of a sudden the person doesn't have eyes or thumbs..." "Well, I'm concerned is do the doctors really tell you what they know about you? And if they are really telling you the truth of everything they know."  
*"The bottom line is just that you hope ... you hope that somebody in the lab is doing the right thing."*
- 41 responses (25%) related to concerns about healthcare costs and insurance and employment discrimination.  
*"... But I have heard that if insurance companies find this out [a family history of breast cancer] they will drop you although they are not legally supposed to do that."*
- 18 responses (11%) concerned cloning and stem cell research.
- 16 responses (10%) spoke to religious and ethical concerns.  
*"You're trying to play God. Somebody is trying to play God."* "Cloning is against God's law."
- 11 responses (7%) related to the potential psychological and social impact of genetics in medicine. The list of concerns included such things as testing people but not having a treatment; making decisions about who you will marry based on test results; making decision about who you should tell.
- In one group only, 6 responses (4%) related to the potential problems that might arise if people begin living longer.

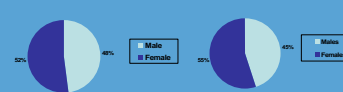
➢ **Are there benefits in using genetics in medicine? If so, what are they? (52 responses, 13 respondents (25%) were speaking from personal experience)**

- 24 responses (46%) related to the benefit of identifying people susceptible to disease, and the advantages of knowing you are at risk. They spoke about the benefits of early treatment, prevention, and the ability to prepare for the future and make decisions about whether or not to have children.  
*"... But their knowledge of those genetics has them to -- to do things to help prevent it to look for preventive medicine and to be aware of the things that are coming in, and know what they can do to prevent it."*
- 11 responses (21%) related to the potential benefits of current or future research in the field.
- 5 responses (10%) related to the potential benefits of pharmacogenetics.
- 12 responses (23%) were more general in nature talking about potential healthcare savings, improving the quality of life, increasing longevity, eradicating disease, and finding out the underlying cause of a child's problem.
- **If you could have a genetic test or family history evaluation with a genetic counselor to predict whether you were personally at increased risk for health problems, would you? (89 responses)**
- 46 respondents (52%) reported that they would pursue an evaluation. However, of these 16 (35%) respondents qualified their answer stating that it depends of the test, if there are no out-of-pocket expenses, only if it would help my children, if my insurance won't go up, if I were younger, and:  
*"If you could take preventative medicine to maybe turn it back and not get the disease."*
- 34 respondents (39%) indicated that they would not pursue an evaluation. 19 (56%) respondents qualified their answer. 6 were "scared" to find out the results. 3 took a fatalistic approach "If I know I'm gonna die at 50 why bother". 3 thought that knowing might cause it to happen. *"I wouldn't want someone to say, 'Ok, you're a prime target for a stroke.' And, as Tom said, I would go home and have a stroke."* 2 respondents didn't want to have to worry about the results and the 5 listed other reasons such as it against God's plan, and it may change my life.
- 6 respondents (7%) would only pursue an evaluation under certain circumstances or approved of it for younger people.
- 2 respondents (2%) expressed ambivalence
- **How do you usually get information about health and medical issues? What do you think is the best way to let people like you know about genomic medicine? (213 responses)**
- 15 different resources were mentioned. The top three were: The internet – 47 responses (15%), Television – 44 responses (14%), Doctor/Doctor's Office – 35 responses (11%)  
*"Also, the doctor is going to have to tell me, because when I come inside there I'm usually concerned about what's wrong with me..."* "Pamphlets in the doctor's office." "In the actual rooms you can wait for 20 minutes, by that time I read everything on the walls"
- During this discussion 78 responses were made regarding how the information should be presented regardless of the vehicle. Respondents felt strongly that the information should be personalized, written in laymen's terms, made easily accessible, and provided by credible sources.

### 2000 U.S. Census Data Guilford County, NC



### Focus Group Participants



## CONCLUSIONS

- **Only a small percentage of people know about the use of genetic information in medicine.** What they know is often based on their own personal experiences or what they have read and this may be incorrect.
- **The list of concerns far outweighs the perceived benefits of using genetic information in medicine.** The majority of concerns reflect a distrust of scientists, doctors, and the government. People are concerned about how the information will be used, and that it will lead to increased healthcare costs, health insurance discrimination and employment discrimination.
- **Perceived benefits reflected respondents desire for information about their future health and the potential for better treatments, prevention of disease and cures.** Respondents also mentioned preconception counseling and diagnosis as benefits. In these instances they were all speaking from personal experience.
- **There was only a 16% difference between those who responded that they would pursue a genetic evaluation and those who said that they would not pursue an evaluation.** Responses varied from those wishing to prepare to those who were scared to find out or who took a more fatalistic view towards life.
- **People get medical information from a variety of sources.** Common resources include Internet, personal physicians, TV programs and commercials. Regardless of the source, the information must be personally applicable, easily accessible, credible, and in layman's terms.

## RECOMMENDATIONS

- Educate patients about the use of genetic information in medicine. Use educational materials that explore the use of genetics in medicine, including the pro's and con's of the technology.
- Elicit patient's concern and misperceptions at the start of a visit so that you can specifically address each one. This will help alleviate fears and the feeling that information is being withheld.
- Discuss patients family history and offer risk assessment information. There is an interest in learning risk status for disease, especially if there is treatment or preventative action that can be taken.
- Use a variety of credible information resources for genomic medicine that use laymen's terms and are eye-catching.

## REFERENCES

Condit, C (2001). "What is 'public opinion' about genetics? National Reviews Genetics. 2:811-815.

Litosselli, Lia, (2003). Using Focus Groups in Research. Continuum Publishing, London

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