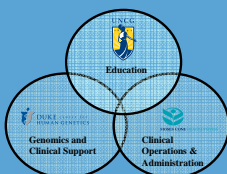




What is GGMI?

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 develop a model system that integrates genomic medicine services into a community health system. GGMI is a comprehensive program, which includes clinical operations, research, and education components. For more information about GGMI see Poster 949.



Need for Community Survey

Education is an essential part of GGMI, as the integration of genomic medicine services into a community health system will hinge, in large part, on the public's perception, acceptance and utilization of these services. To monitor the effectiveness of the educational initiatives, a reliable instrument is required "...to assess the genetic knowledge, attitudes, and beliefs held by the public and to identify areas of misconception or concern that may benefit from public health intervention." (Wang et al., 2005) However, few surveys exist which assess all of these variables (Richards & Ponder, 1996; Jallinoja & Aro, 1999; Henneman, Timmermans, & van der Wall 2004; Lanie et al., 2004), and those that do are often disease-specific or limited in scope (Sanderson et al. 2004; Bottoff et al., 2002; Bunn et al., 2002; Furr & Kelly, 1999).

One goal of this project was to develop an instrument and conduct a baseline educational needs assessment of English speaking residents in Guilford County, over age 18. A pilot instrument was developed and modifications were made based on the pilot data. The modified instrument was then used to conduct the community survey. The instrument is posted on the GGMI website (www.genomic-medicine.org).

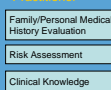
Methods

Survey Development

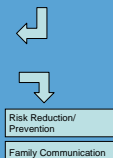
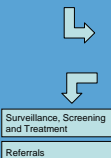
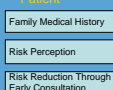
The knowledge portion of the survey is based on the overall goal of our educational initiative, to facilitate point-of-service education between primary care providers and their patients. To promote these conversations, we developed three overarching themes for our community, patient and healthcare providers' education initiatives:

- Family health history is central to genomic medicine.
- Healthcare recommendations exist for people at increased risk for certain diseases that may reduce their risk or delay the onset of disease.
- At this time, genetic testing for susceptibility genes is appropriate for only a subset of people at increased risk.

Providers



Patients



Considerations in Developing Educational Objectives

- NCHPEG Core Competencies in Genetics Essential for Health Care Professionals
- The role of family health history in the assessment of risk for the common complex diseases
- Lack of familiarity with genomic medicine on the part of the community and health care professionals
- The general perception among professionals and lay people that genetic testing is the first step in the risk assessment process
- The mistrust of the health care system expressed by people who participated in our focus groups

In addition to questions that assess knowledge, questions were also drafted to assess respondents':

- Confidence in regulatory agencies
- Perception of the usefulness or anticipated uses of the technology
- Moral code

These categories were selected because they also impact peoples' attitudes about genetics and genetic testing.

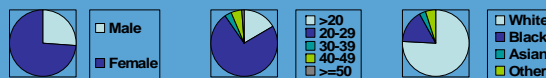
Key Results From the Pilot Survey

The pilot survey was distributed to students enrolled in six courses on the UNCG campus:

- General Psychology (2)
- Principles of Microeconomics
- Economics of Entrepreneurship
- Teaching as a Profession
- Graduate Course in Nursing

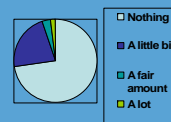
301 students completed the survey. The respondents were predominantly female (74.1%) and Caucasian (74.8%) with a mean age of 23. This is representative of UNCG's campus.

Demographic Data:



Awareness:

When asked, "How much have you personally heard about genomic medicine?" 72.4% of respondents said "nothing", 22.6% said "A little bit" and 5% reported that they had heard "A fair amount" or "A lot".



Knowledge:

40% of respondents correctly answered at least 75% of the questions (11 of 14) with a reliability of 0.213 (KR20). We understand that the reliability was low because we were using true/false questions.

36% of respondents correctly answered the question "It is possible to do a genetic test for most of the common diseases." This points to a general misunderstanding of the available technology.

68% knew that "It is against the law for insurance companies to deny health insurance to some people based on the results of a genetic test."

89% of respondents correctly answered the question "In North Carolina it is against the law for employers to treat one person differently than others based on the results of a genetic test." A high percentage of students are knowledgeable about their legal rights related to genetic testing.

Attitudes:

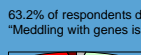
87% of respondents disagreed or strongly disagreed with the statement "Genetic testing makes me uncomfortable from a moral standpoint."



67.1% of respondents disagreed or strongly disagreed with the statement "I worry that genetic testing will ultimately lead to human cloning."



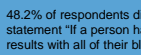
63.2% of respondents disagreed or strongly disagreed with the statement "Meddling with genes is like playing God."



86.4% of respondents disagreed or strongly disagreed with the statement "Genetic testing should not be done."



48.2% of respondents disagreed or strongly disagreed with the statement "If a person has a genetic test, they should share their test results with all of their blood relatives."

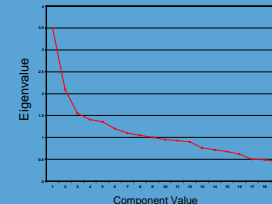


74% of respondents thought it unlikely that "All genetic tests will become mandatory."

60% thought it was likely that "Insurance companies will ask for a genetic test before deciding how much to charge a person for health insurance."

76% thought it was unlikely that "Employers will require people to take a genetic test before they are hired."

Scree Plot



Principal Component Analysis

There was a high correlation in the answers to the three questions regarding moral attitudes, thoughts on human cloning, and playing God. There was also a correlation in the answers to the three questions regarding the potential use of genetic technology.

Conclusions

The majority (95%) of students had not heard of, or know very little about, genomic medicine. Respondents' attitudes towards genetic testing are generally favorable. Students believe that it is unlikely that genetic testing will become mandatory or used by employers in the hiring process. They did, however, express concern about insurance discrimination.

The pilot instrument was effective in measuring respondents' moral code and their perceptions regarding the anticipated uses of genetic technology. However, because of low reliability in the knowledge questions they were subsequently modified to add a category to reduce the amount of guessing. These revisions have been applied to the community survey.

Based on the analysis of the students' responses and their feedback, questions were reworded, added, or deleted for the community survey. Additional questions were added to the attitudes section to better capture respondents' confidence in regulatory agencies. The revised instrument was used to survey a random sample of 1136 Guilford County residents in July and August of 2006.

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