



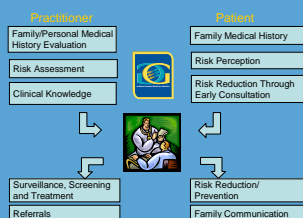
What is GGMI?

The Guilford Genomic Medicine Initiative (GGMI) is a collaborative demonstration project to develop a model system that integrates genomic medicine services into a community health system. GGMI is a comprehensive program, which includes clinical operations and an education component.



Rationale and Need for Genomic Medicine Model System

The Human Genome Project has stimulated a frenzy of research and increased knowledge. Applying that knowledge to health and disease is a natural extension of genetic medicine (Guttmacher, 2007). Genomic medicine has been defined as the use of genetic information to improve health outcomes (Khoury, 2000), and has been heralded as the future of current medicine, moving medical practice from a reactionary system to a proactive system. It has been foretold that by 2010 predictive genetic tests will be available for many common diseases (Collins, 2001). The demand for predictive services, will start to overwhelm the current genetics model, and transform the practice of genetics into the healthcare of many rather than the healthcare of few (Guttmacher, 2001). Healthcare professionals from other areas of expertise, including family practice and internal medicine, will need to be prepared for the influx of patients seeking genomic medicine services. In order to be prepared for these patients, healthcare professionals must be educated on the importance of risk assessment, counseling, and identifying individuals who are at greatest risk for possible genetic testing.



Methods

Overall Education

Educational Goals

The conceptual framework that was chosen is a three-pronged educational program with complementary educational goals and learning objectives for each audience. The educational goals include:

- Residents of Guilford County will begin to collect their family medical history and share this information with their primary care providers. Residents will also be able to cite the legislation regarding privacy and confidentiality of genetic information.
- Patients at increased risk for breast and ovarian cancer, colon cancer, and thrombophilia will be able to describe the various medical management options they can consider based on their level of risk.
- Physicians will be able to identify patients at increased risk for these disorders, and use this information to develop individualized medical management plans.

Educational Objectives

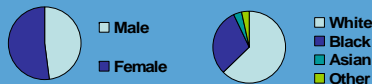
Although it will differ in detail for each audience, the content and ultimate objectives to promote health and reduce disease risk are the same. The following is the first 3 of 22 objectives of the major topics/concepts that will be covered.

The Lay Public	Patients at Risk	Healthcare Providers
Genomic medicine involves the use of a person's genetic information to improve his or her health outcomes.	Genomic medicine involves the use of a person's genetic information to improve his or her health outcomes.	Genomic medicine involves the use of a person's genetic information to improve his or her health outcomes.
Virtually all disorders have a genetic component.	Virtually all disorders have a genetic component.	Virtually all disorders have a genetic component.
A person's health is determined by the interaction between his or her genes, lifestyle, and the environment.	A person's health is determined by the interaction between his or her genes, lifestyle, and the environment.	Expression of a common complex disorder is influenced by the products of multiple genes interacting with environmental factors throughout development, maturation, and aging.

Needs Assessment

An integral component of GGMI is to develop and implement a comprehensive educational program that can be used in Guilford County and is transferable into other communities. To obtain this, we must get involvement from all stakeholders for the project to be successful. Hannum (1989) describes the needs assessment as a way to help identify the gaps between the current knowledge and the desired educational outcome. A needs assessment is imperative, prior to starting an education program, to help determine how best to reach the target audience in a manner that will be conducive to both education on the project and buy-in from the community.

Guilford County
Population: 429,603



Patient and Community Education

In order to obtain involvement from the community, the education piece will be crucial (Jallinoja and Aro, 1999; Davison et al, 1997). Our target audience is English speaking, Guilford County residents aged 18 or older. The needs assessment guides our community education. Our community needs assessment included:

- Literature/Existing Education Review
- Community Survey
- Community Focus Groups
- Community Advisory Committee

Healthcare Professional Education

In order to obtain involvement from the healthcare professional community we have targeted family practice and internal medicine physicians practicing in Guilford County, NC. Our needs assessment guides our education endeavors:

- Literature and Educational Program Review
- Physician Interviews
- Focus Groups

Proposed Education Strategies

The goal of the initiative is to develop effective community-based programs which recognize the importance of family medical history. Overarching themes were created that provide a guide for all education programs.

These themes include:

- The family history is central to a genetically based approach to health care,
- Only people who are at increased risk are referred on for further in-depth assessment,
- At this time, genetic testing for susceptibility genes is appropriate for only a subset of people at increased risk, and
- While state and federal laws already exist to protect people from genetic discrimination, there are gaps in protections.

Adult learning theory was used to 1) develop the conceptual framework, 2) choose the topics to cover, and 3) decide on our methods of instruction.

Community Education

To receive the benefits of genomic medicine, community members are already being instructed to collect their own family health history. Members of the community will also be encouraged to share their family health history with their doctor, which may, in turn, result in a consumer driven need for other physicians in Guilford County to take our on-line courses.

Educational activities for the Community include:

- Website
- Health Fairs
- Presentations
- Town Halls
- Community Newsletter
- Bulletin boards for partner organizations

Patient Education

Patient education will occur at the point-of-service. A needs assessment will be performed following the interaction between patients and their providers to ascertain what additional resources they require, and the best method for distributing these resources. Education strategies for patients may include such things as:

- Web-based resources
- Brochures on target diseases
- Posters
- Genetic Counseling

Healthcare Professional Education:

A case based approach was selected when developing the on-line educational modules for physicians. The physicians who are participating in the Initiative are particularly motivated to learn more about the stratification of patients into risk categories and the management strategies recommended for individuals at increased risk, as it is their patients who will be participating in this project. Educational strategies for physicians include:

- Web-based resources to complement the modules
- On-line educational modules with evaluation
- Grand Rounds
- Informational presentations
- Consultation services via phone or email

Conclusions

The Guilford Genomic Medicine Initiative (GGMI) is a novel demonstration project. It is the first of its kind to try and define how Genomic Medicine should be practiced within a community healthcare system. We are creating a system of education that facilitate point-of-service conversation between healthcare providers and their patients. The learning objectives for each population mirror each other in an attempt to reach this goal. We are limiting our scope of educational programs to those topics that relate specifically to the promotion of this goal. We have identified the knowledge, attitudes and opinions of our community and are working closely with the healthcare providers in the area to determine their needs in order to achieve acceptance of genomic medicine within the medical community and individual practices. Evaluation measures will be vitally important to ensure that our strategies have made measurable differences in the acceptance and practice of genomic medicine in each population.

References

- Core competencies in genetics essential for all health-care professionals. Core Competencies Working Group of the NCHPEP. 2000.
- Collins F.S. (2001). Implications of the Human Genome Project for medical science. *JAMA*, 285:540
- Emery J., Watson E., Rose P., Andermann A. (1999). A systemic review of the literature exploring the role of the primary care physician in genetic services. *Family Practice*. 16:426-445.
- Guttmacher A.E., Jenkins J., Uhlmann W.R. (2001). Genomic Medicine: Who Will Practice It? *A Call To Arms*. *Am J Med Genet*. 106:216-222.
- Guttmacher A.E., Porteous M.E., McInerney J.D. (2007). Educating health-care professionals about genetics and genomics. *Nat Rev Genet*. 8(2):151-157.
- Hannum W. Institutional Systems Development in Large Organizations. Englewood Cliffs, NJ: Educational Technology Publications, 1989.
- Jallinoja P, Aro AR. (1999). Knowledge about genes and heredity among Finns. *New Genetics and Society*, 18(1):101-110.
- Khoury MJ, Burke W, Thomson, EJ. Genetics and Public Health in the 21st Century: Using Genetic Information to Improve Health and Prevent Disease. 2000. Oxford University Press. New York. New York

ACKNOWLEDGMENTS

This work was performed under the auspices of the "Guilford Genomic Medicine Initiative (GGMI); Margaret Pericak-Vance, Ph.D., (PI), Jeffery Vance, Ph.D., M.D., Susan Blanton, Ph.D., Susan Hahn, M.S., (Miami Institute of Human Genetics, University of Miami, FL), Marcy Speer, Ph.D., Mark Donahue, M.D., Celette 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., Carol Christianson, M.S., Leslie Evans, M.S., Debra Wallace, Ph.D., Susan Lietz, Ph.D., (The University of North Carolina at Greensboro); Pamela Lietz, MBA, Astrid Ajajaja, MA (Moses Cone Health System). GGMI is supported by funding from the U. S. Department of the Army (W81XWH-05-1-0383). A special thank you to Tiese Rotbury who helped with the data analysis of the community survey, and to Joe McInerney MS, Cindy Prows MSN, Mark Lubanski, MD, and Ann Swiford MS, MD for their guidance during the development phase of the educational initiative.