

# The Guilford Genomic Medicine Initiative (GGMI): Developing a model for personalized medicine

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## ABSTRACT

Genetic information has the potential to revolutionize medicine by changing it from a discipline that reacts to disease to one that prevents it. The main soldiers of this revolution will be the exiting primary and specialty physician practices in the private, not the University, setting. However, in a recent survey, only 8% of medical directors believed they were prepared to provide even the most basic education, decision support and assessment of risks for their patients in a genomic medicine setting. To this end, the Moses Cone Health System of Greensboro, NC, UNC at Greensboro, and the Center for Human Genetics at Duke University have begun the GGMI. Its goal is to create a working model to address the specific problems in reengineering current medical systems to be genomic medicine ready. GGMI will create solutions that can be applied to other medical plans, such as the military's. The specific aims are to create first a baseline genomic literacy in the general and medical community and to then use a step-wise implementation of three initial diseases to develop a genomic medicine model. Focus groups, both lay and professional, have been conducted to ascertain the level of education and interest in genomic medicine. For the first aim, a web-based genetic and family history module has been developed for physician education. The diseases considered initially in the second aim are those in which the genomic information is clearly and universally agreed to be beneficial as a single test and have wide appeal to the population as a whole. This module includes acquisition of the patient's medical and family history and risk algorithms which generate recommendations based on the family history. Algorithms for thrombotic disease (Factor V Leiden) and breast and colon cancer have been developed and are being piloted in select private practices. Genomic medicine for pharmacogenetics will be developed next. Update of the progress and model development paradigm will be presented.

## INTRODUCTION

Genomic medicine uses an individual's genetic information to improve health outcomes. In practice, this may include: (1) identifying individuals at increased risk for disease when prevention and early detection is most effective, (2) diagnosing disease, and (3) treating existing disease. It also has the potential to reduce medical costs by providing better care for the individual patient, rather than reducing costs by limiting access. Despite ever increasing research discoveries, little investigation has focused on how genomic medicine will begin. One thing is obvious: no longer will a few thousand genetic specialists be able to handle the genetic needs of the public. Genomic medicine is unique in that it affects all specialties. Furthermore, while the promise and reach of genomic medicine is vast, incorporating its use into the health care infrastructure is complicated. Challenges include educating the community, health-care professionals, and the patients they serve, and numerous technical, logistical, and operational challenges.

There is a call for an initiative to model a healthcare system's comprehensive adaptation to include genomic medicine. GGMI will apply broad-based educational programs, clinical procedures, and outcome assessments that utilize the unique strengths of its partners and bring the benefits of genomic medicine to the community.

## STUDY DESIGN

1. Implement a program to educate the lay community, health professionals, and the patients they serve about the relevant practical and ethical, legal, and social issues that pertain to genomic medicine. Our education initiative includes comprehensive curriculum development - needs assessment, development, implementation, and evaluation.

### A. Needs assessment of target populations

1. Assess baseline knowledge and attitudes of target populations in our community utilizing surveys, focus groups and interviews

### B. Develop and implement education programs/tools

1. Community - lectures, health fair and other exhibits, community forums, articles, media messages, posters, brochures, flyers, and web-site (www.genomic-medicine.org)

2. Health Professional Education – lectures, workshops, education modules, resource manual, genetic counseling resource person, and web-site

3. Patient Education – brochures and web-site information

\* For more details on the GGMI education focus, please see poster #950.

2. Implement strategies to facilitate the use of genomic medicine advances in the community healthcare setting, beginning with primary care

### A. Needs assessment

1. Review existing data and resources from other projects pertaining to implementing needed aspects of genomic medicine such as infrastructure, family history tools, and risk algorithms

2. Assess current community healthcare infrastructure and uses of genomic medicine in our target population

### B. Clinical pilot program to develop the model

1. Educational materials for providers and patients (as above)

2. Master database (data repository) at Moses Cone Health System (MCHS) to facilitate the GGMI for storing, querying, and updating personal genomic medicine information and outcome variable data

3. Computer-based self administered family history and genetic risk assessment tool to facilitate the practice of genomic medicine

Risk assessment will rely on a self-administered computer tool that collects personal and family medical history that can be retained, updated, and queried. The tool, named GRASSroots (GGMI Risk Assessment), generates a report for providers for use in tailoring care. Based on patients' entries in the Assessment Tool, patients will be placed in one of three risk categories described with a functional label for breast, ovarian, and colon cancers and thrombosis. Ultimately, pilot disorders were chosen because genomic medicine advances have been proven beneficial. Furthermore, they are common, influenced by family and personal medical history, and because genetic testing is available for those at highest risk.

Risk Categories:

**Follow routine guidelines** - none of the factors we measured placed the patient at increased risk

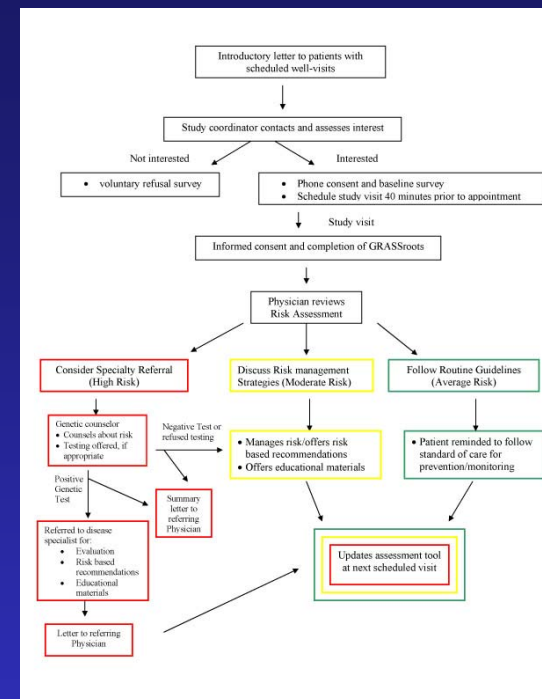
**Discuss risk management strategies** – risk is increased, but not enough that a genetic counseling referral would be appropriate; and

**Consider specialty referral** – risk is high enough that genetic counseling is appropriate.

4. Genetic counselor provided to lend ongoing educational support and provide counseling to those participants at highest risk.

5. Implement voluntary DNA databank to apply pharmacogenetic strategies.

## Patient Flow



## SUMMARY

To date, no projects have examined the interaction of all components of genomic medicine described above. Examples exist where these components were utilized individually, thus laying the groundwork for the larger demonstration. The GGMI represents the first comprehensive introduction of genomic medicine into a community health setting. The model that is developed to implement genomic medicine and outcomes measured to verify effectiveness may later be applied to the military system and other health care systems around the globe.

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