

**Genetics in Primary Care (GPC): A Faculty Development
Initiative**

HRSA Contract 240-98-0020

EXECUTIVE SUMMARY

DECEMBER 19, 2003

**Contractor:
Society of Teachers of Family Medicine
11400 Tomahawk Creek Parkway
Suite 540
Leawood KS 66211**

September 1998 – December 2003

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Executive Summary

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Background

The Genetics in Primary Care (GPC): A Faculty Development Initiative has been conducted in three phases over five years (September 1998- December 2003) through a contract from the Maternal and Child Health Bureau (MCHB) of the Health Resources and Services Administration (HRSA) to the Society of Teachers of Family Medicine (STFM). Cofunding of the project was provided by the Bureau of Health Professions, HRSA, the National Human Genome Research Institute (NHGRI), National Institutes of Health, and the Agency for Healthcare Research and Quality (AHRQ).

The goal of the GPC Faculty Development Initiative was to enhance the ability of faculty to incorporate the clinical application of genetic information into undergraduate and graduate primary care medical education.

The GPC contract was awarded for three years (September 1998- September 2001). However, as subsequent needs were identified to fully implement the scope of work, the GPC contract was modified to extend the project by 27 more months. All delivered products, subcontracts, quarterly and other written reports, contract modifications, announcements, selection of faculty teams and consultants were approved by the Federal Project officer from the MCHB, HRSA. An overall timeline of the GPC Project is provided on the following page.

Phase I of the project, approximately the first 18 months, was devoted to organization, planning, and development. Formation of the Executive Committee with specific input from a Genetics Education Consultant Committee and formation of a larger Advisory Committee, representing 37 organizations, were key components of Phase I of work.

Phase II (approximately 2.5 years) was devoted to implementing a faculty development program (the GPC Training Program) which was developed by the Executive Committee and the Genetics Education Consultant Committee with significant input and involvement from the Advisory Committee. Continued work in Phase II was made possible through a contract modification at the end of the third year which allowed four workgroups to undertake collaborative work.

Phase III (the final 15 months of the project) was devoted to providing the opportunity for: 1) the four workgroup leaders to meet with the Executive Committee liaisons to the workgroups to consider designs of pilot studies of the draft workgroup products; 2) the Executive Committee to hold one final meeting with the Advisory Committee for purposes of obtaining input into the final report to the government; 3) workgroups to prepare draft manuscripts; and 4) the Executive Committee to complete contract reporting requirements.

GPC TIMELINE

❖ Phase I: Organization, Planning and Development

September 1998-June 2000

- Form Executive and Advisory Committees and Genetics Education Consultant Committee
- Identify Evaluation Consultant for the project
- Select an External Evaluator
- Develop a Master Plan to include a Program Outcomes Evaluation Plan

❖ Phase II: Implement Faculty Development Education and Training Projects

July 2000 – September 2001

- Select faculty teams (through national competitive process) to participate in GPC Training Program
- Hold Parts I and II of the GPC Training Program
- Implement faculty development activities at teams' programs/institutions
- Conduct site visits to faculty teams' programs/institutions
- Conduct external evaluation activities

October 2001-September 2002 (funding continued through Modification #4 to the contract)

- *Based on input received from the GPC faculty teams, site visitors, Advisory Committee, and external evaluation team, Phase II of implementation was extended until September 2002 to include continued collaborative work with the GPC faculty teams through four workgroups.*

❖ Phase III: Complete Evaluation and Make Recommendations to Funders

October 2002 – December 2003

- GPC External Evaluation Team complete final report on evaluation of the GPC Training Program
- GPC Workgroup Leaders and Executive Committee Liaisons meet to discuss design(s) of pilot study(ies) of products

- Hold final meeting of the GPC Executive and Advisory Committees to receive input from the Advisory Committee into recommendations for the final report on the GPC Project
- GPC Executive Committee complete GPC Project reporting requirements

Formation of the GPC Executive and Advisory Committees

An interdisciplinary Executive Committee (EC), codirected by a family physician, general internist, and general pediatrician, was named to lead the project. A geneticist educator, resident, medical student, project administrator, and project manager worked together with the three codirectors as members of the EC. The codirectorship from general internal medicine was provided by two leaders (serving consecutively), one serving from 1998-1999 and the second serving from 2000-2003.

An eleven-member Genetics Education Consultant Committee (GECC), under the direction of the geneticist educator member of the EC, brought to the Executive and Advisory Committees expertise pertinent to development of the GPC Training Program (i.e., contract Master Plan) in Phase I. Toward the end of Phase I, a curriculum specialist was hired to work with the Director of the GPC Training Program and Executive Committee to develop the training program.

Thirty-seven organizations were represented on the GPC Advisory Committee. These organizations (see *Attachment 1*, page 20) represented a broad range of constituent groups from primary care, genetics and other medical specialty groups.

GPC Training Program

The GPC Training Program Design incorporated the following structural elements:

- A. Team approach.** GPC training focused on faculty teams of “exemplars,” consisting of family medicine (fm), general internal medicine (gim) and general pediatrics (gp) faculty targeted by the contract. This targeted membership within each team was to be supplemented with other faculty, as necessary, to enable faculty development activities by targeted fm, gim and gp faculty at home institutions.
- B. Team composition.** It was envisioned that each team would be composed of 3-5 members, consisting of at least three targeted faculty (fm, gim, gp). A geneticist faculty member was recommended (i.e., it was required that there be genetics expertise on the team). It was envisioned that a fifth member

might be another targeted (fm, gim, gp) member or another faculty member who could facilitate faculty development activities at the home institution.

C. Competitive selection of teams. Applicant teams from residency programs and medical schools/colleges of osteopathic medicine competed for selection. Final selection of the participating teams was based in part on the aggregate representation of fm, gim, gp faculty across all teams and on aggregate representation of faculty who were primarily teachers, faculty who were teachers, researchers and/or administrators, and faculty who were leaders.

D. Train the trainer model. GPC faculty teams were expected to implement faculty development activities at home institutions as part of their participation in GPC training. To support teams in implementing faculty development at home institutions, the GPC Training Program was to incorporate the following features:

1. Two training sessions spaced six months apart so that teams could apply what was learned at the first session back at home institutions;
2. Support through mentorship from GPC faculty during the six-month implementation period;
3. Faculty development at home institutions was to be based on needs assessments conducted by the faculty teams prior to attending the first training session;
4. Long-term tracking and evaluation of the individual teams' faculty development efforts, including plans to meet expectations of scholarly products of their work through presenting at national meetings or publishing;
5. The second training session was to focus on what was learned by individual teams and across teams, through evaluation findings from both the external evaluation of GPC as well as from evaluation by individual teams of their own efforts; and
6. The second training session was to provide a synthesis of what was learned and what might be generalizable.

E. Support for team participation. Each team selected to participate in the GPC Training Program was to receive a stipend (\$10,000) to support members' participation. Teams' travel to Parts I and II of the GPC Training Program was to be funded by the parent contract.

The following were key content features of the GPC Training Program:

1. Case-based curriculum

The GPC developed a curriculum to train faculty which was largely case based and interactive in nature. Additionally, the case-based format of the

curriculum was intended to be helpful in elucidating the essential content and contextual issues at the core of the interface between primary care and genetics. This case-based methodology was piloted through the *Genetics for Primary Care Providers* course at the first meeting of the GPC Executive and Advisory Committees. A summary of points emerging from this course with regard to the interface between genetics and primary care and how that could be elucidated through case-based instructional methods was developed.

2. *Curriculum intended to be adaptable to variety of teaching settings.*
The intent was for the curriculum to be adaptable to a variety of teaching settings (i.e., to teach faculty responsible for educating students in clerkships or residency faculty responsible for training primary care residents).
3. *Combined training with tracks.*
Parts I and II of the GPC Training Program included combined training for all team members coupled with specific training along three tracks. The tracks would focus on knowledge and skills of particular interest to team members whose primary faculty responsibilities were that of a) clinical teacher, b) teacher/researcher/administrator, or c) leader.
4. *Focus on local resources.*
Teams were asked to identify local and regional resources as part of their application.
5. *Focus on use of existing genetics education resources.*
Teams were to become familiar with national resources as part of their participation in the training sessions. Hands-on instruction accessing resources via computers and the internet was incorporated into the training sessions.
6. *Learners as catalysts.*
Team members were encouraged to bring real questions from home learners (i.e., students and residents) into the training sessions as they developed concrete plans for faculty development activities in home institutions or programs.

Selection of Faculty Teams to Participate in the GPC Training Program

A Request for Proposals (RFP), incorporating the above characteristics, was issued in April 2000 to identify faculty teams to participate in the GPC Training Program. Fifty-three proposals were received in response to the GPC RFP. Proposals were reviewed based on the team composition requirements and the review criteria in the RFP. As stated in the RFP, selection of teams was based on the outcome of the review and on consideration of aggregate characteristics

across the teams, including a balance of family medicine, general internal medicine, and general pediatrics physician faculty team members, mix of faculty whose responsibilities were those of clinical teacher, teacher/administrator/researcher, and leader, geographic representation, and a variety of models.

Given the large response to the RFP, the Executive Committee and Project Officer discussed the ability to accommodate more than ten teams. It was agreed that twenty teams could be accommodated. The following twenty teams (listed alphabetically by the program/institution names) were selected to participate in the GPC Training Program:

Baylor College of Medicine
Boston University School of Medicine/Boston Medical Center
Cedars-Sinai Medical Center
Cook County Hospital/Rush Medical College
East Carolina University, Brody School of Medicine
Lancaster General Hospital Family Practice Residency Program
Mayo Clinic
Medical College of Wisconsin
New York Medical College
Palmetto Health Alliance/University of South Carolina School of Medicine
State University of New York School of Medicine at Buffalo
University of California, Los Angeles School of Medicine
University of Cincinnati College of Medicine
University of Florida College of Medicine
University of Maryland School of Medicine
University of Oklahoma Health Sciences Center – Tulsa
University of Utah Health Sciences/Primary Children’s Medical Center
University of Vermont College of Medicine
University of Washington Family Practice Residency Network
Vanderbilt University Medical Center and Meharry Medical College

Leaders of the twenty accepted teams were asked to submit the top three needs of their teams to the Executive Committee by August 1, 2000. The greatest area of need expressed by team leaders just prior to entering the GPC Training Program was related to curriculum resources, and educational resources for teaching genetics in primary care.

Conduct of the GPC Training Program

The GPC training program was a two-part train-the-trainer program to enhance the ability of primary care faculty to incorporate the clinical application of genetic information into undergraduate and graduate primary care medical education.

The dates for Parts I and II of the GPC Training Program were scheduled six months apart so as to allow faculty team participants time to implement faculty development activities at their home institutions between the two sessions. Parts I and II of the GPC Training Program were held October 10 - 12, 2000 in the Chicago, Illinois area and April 4-6, 2001 in the Washington, DC area, respectively.

GPC Faculty Trainers for the Training Program were identified from among interested members of the Genetics Education Consultant Committee and the Advisory Committee. Objectives of the Part I of the GPC Training Program aimed to ensure that faculty team participants would be able to:

1. Understand and articulate the purpose of incorporating genetics into primary care teaching and practice;
2. Identify specific learning needs for home institutions regarding incorporating genetics into primary care teaching and practice;
3. Develop an implementation plan for addressing the learning needs at the home institution for the next 6 months;
4. Identify key Web-based and print resources for genetics;
5. Acquire teaching techniques to incorporate genetics into primary care teaching and practice;
6. Acquire teaching techniques and identify resources for addressing ethical, legal, and social implications of genetics in medicine.

Advisors from among the GPC Training Program faculty trainers were assigned to faculty teams to assist with development of faculty development implementation plans at Part I of the GPC Training Program. These implementation plans were revisited by advisors and their respective teams at Part II of the GPC Training Program.

Objectives of Part II of the GPC Training Program aimed at ensuring that faculty team participants would be able to:

1. Identify needs and opportunities for teaching genetics in primary care settings;
2. Demonstrate approaches to teaching genetics in primary care settings;
3. Identify strategies for creating buy-in at home institutions;
4. Share techniques for interdisciplinary work;
5. Participate in case-based discussions of genetics in primary care;
6. Develop revisions to the GPC curriculum;
7. Identify needs and next steps for continuing GPC work.

In between Parts I and II of the GPC Training Program, faculty teams began implementing faculty development activities and teams were visited by two members of the GPC Executive/Advisory/Genetics Education Consultant Committees. These site visits were conducted between February and April 2001. Federal representatives from HRSA, NIH, and AHRQ were notified of the opportunity to accompany site visit teams. Site visitors reported back to the GPC Project Manager following the visits. In addition, the Project Manager conducted organizational teleconferences with visitors prior to making visits.

These visits were structured so as to be of assistance to teams and informational for the visitors. Each visiting team possessed both primary care and genetics expertise. Institutional leaders were encouraged to participate in the site visits. The agendas for the visits were developed collaboratively by GPC faculty team leaders and primary site visitors. The site visits were between 4-8 hours in length and each visitor made between one and four site visits (eleven visitors made one; nine visitors made two visits; two visitors made three visits, and one visitor made four visits).

A total of 23 members of the GPC Executive/Advisory and Genetics Education Consultant Education Committee participated as site visitors. Fourteen Advisory Committee members, 4 Executive Committee members (Project Director, two Codirectors and Geneticist Educator) and 5 Genetics Education Consultant Committee members conducted the visits.

GPC Training Program Outcomes

External evaluation of the GPC Training Program was conducted by a competitively selected team from the Medical College of Wisconsin. External evaluation activities clustered around two GPC Training Program components: 1) Parts I and II of the GPC Training Program conducted off site for faculty teams; and 2) the on-site local implementation of faculty development by teams. A combination of workshop evaluation forms and forms aimed at assessing features of faculty development activities conducted by teams at their home institutions were utilized. A final evaluation questionnaire mailed to all faculty team participants following completion of the GPC Training Program was used for reporting on institutional support and impact of the GPC Training Program and on team members' knowledge of genetic and faculty development principles, and their ability to provide genetics-focused faculty development

Twelve of the 20 (60%) faculty teams provided evaluation data to the external evaluation team. Sixty-five of 99 (66%) of the individual faculty team participants provided evaluation information through the final questionnaire.

At the time of the site visits, prior to the second part of the GPC Training Program, 12 of the faculty teams reported that at least one faculty development

activity had been implemented on site. Following the second part of the GPC Training Program 12 faculty teams provided evaluation data to the external evaluation team relative to faculty development activities conducted on site. These 12 programs reported conducting a total of 16 (range 1-5) faculty development efforts. A total of 859 participants were trained through these 16 events across 12 programs, for an average of 71 participants per program. Types of faculty development activities ranged from noon conferences to half-day faculty workshops and retreats. Some used standardized patients and had developed Websites to deliver information, reinforce, and provide resources to faculty on genetics in primary care education. Clinical faculty were present in the faculty development efforts at these 12 programs. Over 50% of these institutions also had clerkship and course directors and department chairs present at the faculty development sessions. In 14% of these institutions, deans participated in the faculty development activities.

Eighty-five percent of GPC faculty team respondents (66% response overall) reported being adequately to very well-prepared to incorporate clinical application of genetic information into undergraduate and graduate primary care education. Over half of the respondents rated their ability as excellent to good at incorporating faculty development and genetics principles into their teaching. These data suggest progress toward accomplishment of GPC's initial goal to enhance the ability of faculty to incorporate the clinical application of genetic information into primary care medical education.

GPC Curriculum and Workgroup Products

The GPC Curriculum (September 2001 revision) was placed onto the public Website at University of Texas Health Sciences Center in San Antonio, where the Maternal and Child Health Bureau, HRSA houses educational materials. An announcement about the curriculum being placed there was sent via e-mail in December 2001 to all individuals who had inquired publicly about the GPC Project and its materials through the Project Manager.

The materials in the September 2001 GPC Curriculum were designed to serve as a bridge between genetics and primary care. They were not intended as a freestanding curriculum. Each module cites Web-sites for additional background information and articles from the medical literature, including relevant consensus and policy statements where applicable. The modules (listed on the following page) provide a series of teaching cases, developed, with the aim to be representative of patients seen in primary care, while also allowing for the demonstration of genetics issues and principles. The cases are intended to serve as the models for engaging medical students' and residents' interest in genetics topics. For each case, questions are noted and a brief discussion is provided. The additional Websites and other references listed provide the basis for more in-depth exploration of each topic. The eight topics chosen for

development of teaching cases are taken from core areas of primary care practice. These teaching modules were used in the GPC Training Program. They were also reviewed by experts in primary care and genetics for relevance and accuracy.

Modules in the September 2001 revised GPC Curriculum addressed the topics of:

- Breast and Ovarian Cancer
- Cardiovascular Disease
- Colorectal Cancer
- Congenital Hearing Loss
- Dementia
- Developmental Delay
- Iron Overload
- Ethical, Legal, and Social Issues (ELSI)

The September 2001 GPC Curriculum revision is currently available at:

http://genes-r-us.uthscsa.edu/resources/genetics/primary_care.htm

Based on several sources of input (feedback received in April 2001 from the GPC teams at Part II of the GPC Training Program, input received at the fourth (April 2001) GPC Advisory Committee meeting, the summary of reports from GPC site visitors, and the GPC external evaluation team's executive summary of their evaluation of Part II of the GPC Training Program) there was an expressed need for teams to collaborate around production of curricular tools and products which would enhance each team's own productivity and be of potential benefit nationally.

The contract was modified in September 2001 to meet this need. The purpose of this modification was to augment faculty development activities at teams' home institutions through pooling of team members' efforts and expertise. It was anticipated that this pooling of GPC team and Advisory Committee efforts and expertise would yield superior products which would enhance faculty development efforts at GPC teams' institutions and would provide curricular products for eventual national dissemination.

Maintaining collaboration, communication, and the dialogue initiated through the GPC Initiative was an important principle behind continuation of the GPC through this modification. The strategy of forming workgroups with representation from multiple GPC faculty teams and the Advisory Committee members was envisioned to ensure that collaboration and communication, with this necessary expertise, would continue on as broad a level as possible. The role of the

Executive Committee liaisons to the four workgroups was created to help ensure cross-workgroup interaction.

The four content areas addressed by the workgroups were:

- Family History Taking
- Red Flags
- Cultural Competence
- Evidence-based Medicine

Workgroup products developed by the four workgroups included the following:

FAMILY HISTORY TAKING

The family history tool kit consisting of three parts was developed

1. The mnemonic "SCREEN"
2. The Family History Instrument, Parts 1, 2, 3
3. The Second Tier Questions

RED FLAGS

Stand-alone Red Flags Boxes, most with references, were developed for seven of the topics addressed in the Sept 2001 GPC Curriculum modules. An "indications for genetic referrals table" was developed. Additionally, the group developed two substantial revisions to the congenital hearing loss module in the Sept 2001 GPC Curriculum.

CULTURAL COMPETENCE

The Cultural Competence Workgroup developed:

1. a separate module entitled, The Cultural Implications of Genetic Information;
2. the PRACTICE model for thinking about cultural issues in the delivery of genetics in a primary care
3. revisions of seven GPC modules of the September 2001 GPC Curriculum with attention to issues of cultural competency.

EVIDENCE BASED MEDICINE

The GPC Evidence-Based workgroup envisioned a Website linked to other sites. Draft products developed toward this end included a draft word document as a suggestion for a Webpage entitled "How to Utilize these Materials". This draft included links where available on the Internet. Other links were specified as possible in the draft but it was not feasible to portray these in a text document. Introduction to the Web page included a draft review of available websites which would serve as useful linkages to the anticipated web site. Additionally, the group produced an addition to the 2001 GPC curriculum modules on the topic of Fragile X Syndrome.

Between June 17 and July 12, 2002, completed draft products from each of the workgroups were posted to the GPC internal web site at the MCHB's site at

UTHSCSA by the Project Manager. Advisory Committee members, Executive Committee members, workgroup members, and GPC team members who were not on the workgroups but who were members of the GPC Groups list-serve were notified of the site address, how to access it, and of the products being posted for voluntary review.

Final Input from Advisory Committee and Draft Manuscript Preparation

The STFM contract was extended from October 2002-September 2003 for the purposes of a) the Workgroup Leaders and Executive Committee liaisons reviewing all of the workgroup products and designing a pilot study(ies) of the workgroup product(s); b) Executive Committee receiving input from the Advisory Committee regarding recommendations for the final report; and c) final reporting activities undertaken by the Executive Committee.

A meeting of the GPC Workgroup Leaders and Executive Committee Liaisons was held January 11, 2003 to review the workgroup products and discuss pilot study design. A conference call was held February 24, 2003 among members of the GPC Executive Committee and Project Officer to discuss the outcomes of the January meeting.

Through a final modification (#7) to the contract, the period of performance was extended, at no added cost to the government, by three months, from September through December 2003. This allowed the Executive Committee to convene a final meeting of the Advisory Committee in October 2003 for purposes of providing input into recommendations and the draft final report. It also allowed for interested workgroups to devote time and resources to development of draft manuscripts.

Conclusions and Recommendations

The following conclusions and recommendations are derived from an examination of: 1) the organization and implementation phases (Phase I and II) of the GPC Project; 2) the final report from the External Evaluation Team, in particular their recommendations; and 3) consideration of input received from the GPC Advisory Committee at the final meeting of the GPC Executive and Advisory Committees held on October 20, 2003. Prior to that meeting a draft final report was circulated among all GPC Executive and Advisory Committee members, and Genetics Education Consultant Committee members. Then, on site at the meeting, a draft set of conclusions and recommendations to the final report was specifically discussed. Incorporated into the written summary of that meeting was input into the draft report which was received by Advisory Committee members who were unable to attend the meeting.

Conclusions

Phase I: Project Organization

The GPC Project was organized around the concept of viewing genetics through a primary care lens. This concept was the impetus behind the leadership of the project coming through a primary care organization serving as the contractor and through primary care leaders in family medicine, general internal medicine and general pediatrics named as Project Director and Codirectors, respectively, of the project. In reflecting on this leadership focus five years following the inception of the GPC, it is clear that this organization made “in-roads” in helping to establish a national dialogue between primary care and genetics.

As the Advisory Committee reflected at their last meeting in October 2003 on how the GPC Project was organized, there were two issues which arose as important to consider in the future. The first was for future inclusion of OB-GYN as a specialty critically involved in genetics and the future of healthcare in this country. The contract from HRSA mandated certain primary care specialties to lead the project. Future efforts in this area may benefit from looking at broader inclusion, to include OB-GYN. Secondly, by viewing genetics primarily through a primary care lens, much of what has been proven in genetics as directly impacting health outcomes was not emphasized. Future examination of viewing genetics through a primary care lens would benefit from considering how to balance teaching around rare diseases where there is a wealth of knowledge in how genetics impacts health outcomes, versus common diseases seen in primary care, where much less knowledge is available concerning how health outcomes are impacted by genetics alone and/or genetics interacting with the environment.

In forming the Executive Committee, codirectorship by primary care leaders in family medicine, general internal medicine, and general pediatrics was critical. Combining this leadership with a geneticist educator member of the Executive Committee and a Genetics Education Consultant Committee proved invaluable to bringing the optimum genetics and primary care medical education expertise to bear on elucidating the content and a viable approach to the faculty development program of the GPC.

Formation of the Advisory Committee was also critical. Leaders from primary care and genetics were joined with other organizational leaders in a large committee, with much expertise and many perspectives. By including a broad range of 37 organizations represented, the many viewpoints and constituent audiences were reflected in the ongoing discussions and invaluable advice and input from this committee to the Executive Committee in carrying out the project.

The Executive Committee decided early on that the approach to the first Advisory Committee meeting should provide the opportunity to examine issues at the interface between genetics and primary care. The *Genetics for Primary Care Providers* course, held at the first meeting of the Executive and Advisory Committees in September 1999, launched the project in a highly interactive direction and rapidly identified issues which were to be at the core of the GPC Training Program. The Genetics Education Consultant Committee identified a case-based approach as key to bringing out the necessary content and critical issues at the interface between genetics and primary care. This approach to conducting the *Genetics for Primary Care Providers* course initiated an intensive dialogue between the primary care and geneticist members of the Advisory Committee. Some of the cross-cultural issues with regard to genetics and medicine, both historically and present today, were elucidated through this dialogue in a profound way, with some Advisory Committee members commenting that it was a kind of “cross-cultural experience” itself. This dialogue between genetics and primary care on cross-cultural and many other issues initiated through this first meeting of the GPC Advisory Committee is still continuing to progress four years later.

Phase 2: Project Implementation

Forming teams of faculty to develop and implement faculty development at their own sites was effective. Although one person within each team often proved to be the “champion” of the effort, having others to draw on was important to achieving maximum potential impact within complex institutions. Additionally, by requiring teams to be comprised of between 3-5 members, teams were able to identify primary care and geneticist colleagues within their own institution who had varying areas of expertise to carry out teaching and faculty development around genetics.

The RFP requirement to have genetics expertise on each team was critical. It not only provided the needed genetics expertise, but also helped implement faculty development at home sites. One unanticipated outcome of this requirement was that the geneticist team members learned about and developed an interest in primary care. A group of geneticists came together informally during the latter part of Phase II to explore these issues electronically.

Site visits to programs were conducted during the implementation period. This proved to be an effective method of helping to inform the Executive and Advisory Committees about issues experienced on site. Site visits also proved to be helpful to the teams in communicating with institutional leaders about the project.

The External Evaluation Team reported that “many faculty members’ comments conveyed that they were getting much of the ‘what’ to teach but not the ‘how’ to

teach”. Parts I and II of the GPC Training Program were highly intensive and could not provide all of the necessary background regarding content and faculty development expertise. Requiring that teams have faculty development expertise was one mechanism to ensure that teams had adequate skills in conducting faculty development. However, given the complexity of issues regarding genetics and primary care, more time devoted to faculty development skills might have been warranted.

Six months was not long enough for all twenty programs to implement faculty development programs at their home institutions. At the time of the site visits (conducted 4-6 months into the implementation period), twelve teams had completed at least one faculty development session. One might argue that the period for implementation should have been longer. The External Evaluation Team concludes in its final report that “evaluation data indicated that faculty members were more prepared to implement faculty development activities after the second workshop than after the first.” One lesson from an adult learning perspective, however, is that by having a short implementation period, we created a “need to know” which drove faculty to want to learn more. From this perspective, the shorter timeframe for implementation may not, therefore, have been an impediment but part of an entirely appropriate process of faculty development. One lesson may be more clear, however, and that is that six months may be too short a timeframe to create curricular change within institutions.

Advisors were assigned to teams at Part I of the GPC Training Program to help teams complete program implementation plans. Advisors met again with assigned teams at Part II of the GPC Training Program to review progress on implementation of the plans (attempts were also made to assign advisors as site visitors). Assignment of advisors proved to be useful to some teams but not to all. It is possible that there was not enough time within the GPC Training Program sessions to devote to building an “advisor-advisee” relationship. In other cases, teams had articulated needs early and an advisor was in a position to help address these needs. It is also true that some teams were more prepared at the outset to implement faculty development for primary care faculty in genetics than others. The readiness of teams within their own institutional structures and within the faculty development directions already in place at the time of the GPC varied considerably. Therefore, the role of an Advisor to programs varied depending on a combination of the match between the advisor’s expertise and the team’s need, and the overall readiness of the team to implement faculty development in genetics within their institutions.

Recommendations

Recommendations Regarding GPC’s Approach to Faculty Development

1. The approach of bringing teams together to take training back to their own faculty on-site was effective. Requiring representation from primary care and genetics expertise is recommended for future programs with similar aims. Using a case-based, interactive approach to teaching (as is fundamental to the teaching approach when cases are used), is recommended for engaging groups in the dialogue necessary to grapple with and effectively teach issues as complex as genetics in primary care.

2. The GPC Training Program might have provided more needs assessment and evaluation tools for teams to evaluate their own training efforts. Although this was addressed via a simple needs assessment activity prior to Part I of the GPC Training Program, more attention to providing tools to faculty teams for needs assessment and evaluation in future programs is recommended. How teams would use needs assessment tools, however, would vary according to what is already being taught with regard to genetics in primary care at a given institution. So, teams are bound to have differing needs for needs assessment tools and would use tools in different manners.

3. The GPC produced many products for primary care faculty development in genetics (albeit many in draft form by the end of contract funding and still undergoing revisions) through an iterative process. A draft case-based curriculum was taken to the *Genetics for Primary Care Providers* course and was then revised for the GPC Training Program. Following the GPC Training program the GPC curriculum was further revised, reflecting many levels of input and piloting. Emerging from the work of the GPC Executive and Advisory Committees with the faculty teams in using the GPC Curriculum, four content areas arose as important to explore further: cultural competence, family history taking, red flags and evidence-based medicine. Workgroups were formed to develop draft products around these four critical issues at the interface between genetics and primary care. Over the life of the GPC Project, this “hands-on” experience with using draft teaching products led to refinement of existing ones and identification of new areas where teaching products and materials were needed. Creating this kind of iterative process for development of teaching products for faculty development proved to be important in the GPC Project.

4. Being able to fully evaluate faculty development program implementation requires full participation in evaluation by those involved in the faculty development effort. Twelve of the twenty faculty development teams funded through the GPC Project provided evaluation data to the External Evaluation Team. As part of the application, teams were asked to sign a statement of their intention to provide data as requested by the external evaluation team. The Executive Committee might have tied payment of stipend directly to receipt of full evaluation data as one mechanism to ensure that all twenty teams provided data as requested by the External Evaluation Team.

Recommendations to the Funder

1. Collaboration among three federal funders was unique and highly successful with the GPC. By funding through the Health Resources and Services Administration, with cofunding from the National Institutes of Health and the Agency for Healthcare Research and Quality, the broad purview of primary care and genetics was reinforced both within funding agencies and for the broader medical education community.
2. HRSA now has a history of investing funds toward collaborative projects to help move primary care education forward. These are expensive projects due to the large amount of funding required to support the collaborative infrastructure relative to the amount given to institutions. The GPC was another example of a collaborative project with a large infrastructure, which successfully leveraged funding (in relatively small amounts) to move primary care into the future. Consideration of the benefits and momentum generated through this kind of leveraging through a collaborative infrastructure should be given in the future as federal funds are directed toward primary care and genetics educational efforts.
3. The movement of project energy and creativity from faculty teams into workgroup efforts created synergy and tangible outcomes. The funder's willingness to modify the contract to fund this component was responsive. This level of responsiveness by the funder to learning and modifying during the course of a contract is highly recommended. The external evaluation ended with evaluation of the GPC Training Program and ideally might have continued through this phase of workgroup activity.
4. Assuming availability of funds, dissemination of contract products should be a priority, in order to magnify impact of the federal investment in the project. At the conclusion of the project, electronic and web-based communication to appropriate constituents will widely inform the availability of contract products.

Pending the availability of funds, a follow up to the contract could include important dissemination of contract products and findings through an international conference on the integration of rapidly evolving genetic information into the education of primary care clinicians.
5. The rapidly changing nature of the knowledge base, clinical applications, information technology and policy environment for genetics in primary care presented a challenge for all concerned in this project. It will likely prove helpful in dynamic areas like this if in the future federal funders would plan specific opportunities to interlink and coordinate related and/or complimentary grants and contracts. By this means the Federal government could make most efficient use of its investments by fully leveraging the

accumulating breadth of knowledge and experience as well as the expanding network of scholars and resources related to this topic. GPC project examples of how these opportunities arise, and of the successes and challenges to efficient project coordination, include, of course, the Genetics Tools project, as well as the GeneTests Website, the CDC Family History Tools Project, and the SACGT Educational Summit, among others.

Recommendations to Primary care and Genetics Communities

1. A major accomplishment of GPC was the creation a group of academicians from primary care and genetics who have initiated and sustained (at least over the course of the GPC) a dialogue. Future programs drawing on this model of stimulating and sustaining a national dialogue are recommended.
2. The GPC was about marrying genetics with primary care. The GPC initiated a process of bringing primary care and genetics together in a meaningful way. Mechanisms for furthering this dialogue, building on the GPC model of bringing the two communities together to learn together and teach together, are strongly recommended. The work of the GPC workgroups elucidated critical issues at the forefront of the interface between genetics and primary care. Taking the draft products and concepts elucidated in these four areas (cultural competence, family history taking, red flags, evidence-based medicine) and defining a research agenda for the future around the most critical issues is recommended.
3. Five years after the GPC was launched, the purpose of the GPC, as articulated in the proposal to fund the contract, is as compelling as ever. As stated in the Technical Proposal (August 1998), *“Changes in the health care delivery system occurring nationwide bring to the forefront the role of the primary care physician to ensure appropriate care for patients while containing costs. With the rapid growth of knowledge of genetics, primary care physicians need new knowledge and skills to function in this role with regard to genetic diseases. Primary care faculty need to acquire knowledge and skills necessary to teach future physicians how to prevent, diagnose, and manage genetic diseases within the evolving context of the health care delivery system.”* The increasing importance of the work of the GPC and of genetics as primary care evolves toward the future cannot be understated. The importance of genetics factors in disease is important to emphasize in situations where there is a huge evidence base as well as in areas where there is far less evidence. A balanced approach in consideration of the evidence base in genetics is important to maintain as primary care and genetics continue to evolve. Additionally, the ethical, legal, social and cultural implications are going to become increasingly important as more knowledge is gained with respect to the impact of genetics on disease and health outcomes. Continued work in these critical directions is recommended.

ATTACHMENT 1

Genetics in Primary Care (GPC): A Faculty Development Initiative Advisory Committee Organizations

PRIMARY CARE ORGANIZATIONS

Family Medicine

Society of Teachers of Family Medicine
American Academy of Family Physicians
Society of Teachers of Family Medicine Group on Predoctoral Education
Association of Departments of Family Medicine
Association of Family Practice Residency Directors
American Board of Family Practice

Internal Medicine

Society of General Internal Medicine
American College of Physicians
Clerkship Directors in Internal Medicine
Association of Professors of Medicine
Association of Program Directors in Internal Medicine
American Board of Internal Medicine

Pediatrics

Ambulatory Pediatric Association
American Academy of Pediatrics
Council on Medical Student Education in Pediatrics
Association of Medical School Pediatric Department Chairmen
Association of Pediatric Program Directors
American Board of Pediatrics

Other

Medicine-Pediatric Program Directors Association

OTHER SPECIALTY ORGANIZATIONS

American College of Obstetricians and Gynecologists
Association of Professors of Gynecology and Obstetrics
Association of Teachers of Preventive Medicine

OSTEOPATHIC ORGANIZATIONS

American Osteopathic Association
American Association of Colleges of Osteopathic Medicine
American College of Osteopathic Family Physicians

GENETICS ORGANIZATIONS

American College of Medical Genetics
American Society for Human Genetics
Alliance for Genetic Support Groups
Association of Professors of Human Genetics

OTHER ASSOCIATIONS

American Association of Health Plans
American Medical Association
American Medical Student Association
Asian and Pacific Islander American Health Forum
Association of American Medical Colleges
Association of Schools of Public Health
National Hispanic Medical Association
National Medical Association

LISAISONS TO THE GPC ADVISORY COMMITTEE

National Coalition for Health Professional Education in Genetics
National Institutes of Health
Centers for Disease Control and Prevention
Agency for Health Care Policy and Research

Genetics in Primary Care (GPC): A Faculty Development Initiative

HRSA Contract 240-98-0020

FINAL REPORT

DECEMBER 19, 2003

Contractor:

Society of Teachers of Family Medicine

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September 1998 – December 2003

TABLE OF CONTENTS	Page
Preface	3
Acknowledgements	4
Abstract of the Main Text	6
Main Text	10
Background and Introduction	10
Organization of the Main Text	12
Phase I	13
Phase II	21
<i>GPC Training Program Outcomes</i>	28
<i>GPC Curriculum Revision (September 2001)</i>	29
<i>GPC Workgroup Product Development</i>	32
Phase III	39
Conclusions	40
Recommendations	43
Assessment of Degree of Success Achieved	46
 <i>Attachments:</i>	
<i>Attachment 1: GPC Advisory Committee Organizations</i>	47
<i>Attachment 2: Listing of GPC Project Members 1998-2003</i>	49

LISTING OF APPENDICES TO THE FINAL REPORT

APPENDIX A: GPC Request for Proposals (4/00)

APPENDIX B: GPC Site Visit Summary Report (1/02)

APPENDIX C: Final report on evaluation of the GPC Training Program (10/02)

APPENDIX D: GPC Workgroup Product Report and products (10/02)

APPENDIX E: GPC *Dissemination Activity Report* (9/03 update)

APPENDIX F: GPC Draft Manuscripts

F1: Overall GPC Draft Manuscript (12/03)

F2: Cultural Competence Workgroup Draft Manuscript (12/03)

F3: Red Flags Workgroup Draft Manuscript (12/03)

F4: Family History Taking Workgroup Draft Manuscript

PREFACE

The Genetics in Primary Care (GPC) Faculty Development Initiative spanned five years and the transition into a new millennium. The importance of the emerging field of genetics to the education and future practice of primary care physicians has magnified many-fold even since the GPC began in 1998.

Numerous achievements with regard to genetics in primary care and how to better teach students, residents and faculty were accomplished through the GPC. Notably, the training of faculty teams from around the country and the development of curricula and teaching products are some of the accomplishments described in this report. This report serves as the final record of the GPC project and its achievements with recommendations for future directions.

This report chronicles the activities of the GPC over three phases which spanned five years. Issues which arose through the implementation are discussed, and outcomes are detailed. Finally, conclusions and recommendations emerging from the project experience are provided for the government's consideration as strategies for primary care education with regard to genetics are considered.

The success of this complex project is largely due to the contractor, the Society of Teachers of Family Medicine, and the outstanding administrative capabilities of Roger Sherwood CAE, Executive Director of STFM and GPC Project Administrator. Mr. Sherwood's contributions to the smooth flow of the project over three phases are to be acknowledged and commended.

It has been a pleasure to be involved with this highly innovative project. We would like to thank the Maternal and Child Health Bureau and the Bureau of Health Professions of the Health Resources and Services Administration, the National Human Genome Research Institute of the National Institutes of Health and the Agency for Healthcare Research and Quality for this outstanding opportunity.

Norman B. Kahn, Jr. MD
GPC Project Director

Eugene C. Rich, MD
Modena E.H. Wilson, MD MPH
GPC Project Codirectors

ACKNOWLEDGEMENTS

The contractor for the GPC Project, Roger Sherwood, CAE, Executive Director of the Society of Teachers of Family Medicine, gratefully acknowledges the outstanding contributions of the members of the Executive Committee, Genetics Education Consultant and Advisory Committees, the Workgroup Leaders, the members of the External Evaluation Team, and the twenty faculty teams without whom this project could not have been accomplished. Special acknowledgement for the outstanding leadership and tireless efforts are accorded to the Project Director, Norman Kahn, MD, and the Project Codirectors, Modena Wilson, MD, MPH, Steven Wartman, MD, PhD (1998-1999) and Eugene Rich, MD (2000-2003). Their leadership enabled the GPC to be conducted in accordance with the highest possible standards. Contributing to this leadership was the invaluable input to and participation on the Executive Committee by Wylie Burke, MD, PhD and the expertise of the GPC Curriculum Specialist, Kelly Fryer-Edwards, PhD, without both of whom the project would not have achieved its potential. Special appreciation is extended to Ardis Davis, MSW, Project Manager, and Marilyn McMillen, MBA, assistant to the Executive Committee, who helped keep the project on track over its five-year life. Contributions from the student and resident members to the Executive Committee were critical, especially early on as the GPC Training Program was envisioned. Members of the Genetics Education Consultant Committee are also to be commended for their commitment to the project over five years and extraordinarily helpful perspectives and expertise.

The four workgroup leaders, Caryl Heaton, DO, Patrick Jonas, MD, P. Preston Reynolds, MD, PhD and Alison Whelan, MD are to be commended for their extraordinary commitment to seeing that the GPC realize its fullest potential. Their tireless efforts to pulling together workgroup products are very much appreciated and will contribute significantly to furthering primary care faculty development around genetics.

Members of the Advisory Committee are to be commended for their insight, energy and devotion to seeing the project through. The twenty faculty teams are also recognized for their energy, enthusiasm, and contributions to innovations in teaching about genetics in primary care.

Richard Holloway, PhD, and Dawn Bragg, PhD, of the External Evaluation Team and their colleagues at the Medical College of Wisconsin gave their time and energy to fulfill the expectations of the external evaluation of the GPC Project. The performance of the evaluation team in meeting their obligations is to be commended.

Rounding out the work of the team behind the GPC Project are the staff members at the Society of Teachers of Family Medicine and the American Academy of Family

Physicians who gave of their time to facilitate many aspects of project function. In particular, contributions to financial management of the project are to be acknowledged from Dana Greco and contributions to administrative matters from Kay Frank. Additionally, assisting with various administrative functions as demanded by the Project Director at the AAFP, the efforts of Dorothy Young, Diana Swafford and Ruth Coram are recognized and greatly appreciated.

Grateful acknowledgement is also extended to the Associate Administrators of the Maternal and Child Health Bureau and the Bureau of Health Professions of the Health Resources and Services Administration. Particular appreciation is acknowledged for the encouragement of the Project Officer, Michele Puryear, MD, PhD, from the MCHB, and Ruth Kahn, ScD, from the Bureau of Health Professions. Collaborating as cofunders, the National Human Genome Research Institute of the National Institutes of Health, and the Agency for Healthcare Research and Quality are also gratefully acknowledged, without whom the project would not have had the breadth of impact which it realized. In particular the support and encouragement of Elizabeth Thomson, RN, MS, CGC from NHGRI is to be acknowledged and contributions from David Lanier, MD at AHRQ are also greatly appreciated.

Roger Sherwood, CAE
Executive Director

Society of Teachers of Family Medicine

ABSTRACT OF MAIN TEXT

The Genetics in Primary Care (GPC): A Faculty Development Initiative has been conducted in three phases over five years (September 1998- December 2003) through a contract from the Maternal and Child Health Bureau (MCHB) of the Health Resources and Services Administration (HRSA) to the Society of Teachers of Family Medicine (STFM). Cofunding of the project was provided by the Bureau of Health Professions, HRSA, the National Human Genome Research Institute (NHGRI), National Institutes of Health, and the Agency for Healthcare Research and Quality (AHRQ). **The goal of the GPC Faculty Development Initiative was to enhance the ability of faculty to incorporate the clinical application of genetic information into undergraduate and graduate primary care medical education.**

Phase I of the project, approximately the first 18 months, was devoted to organization, planning, and development. Formation of the Executive Committee with specific input from a Genetics Education Consultant Committee and formation of a larger Advisory Committee, representing 37 organizations, were key components of Phase I of work.

Phase II (approximately 2.5 years) was devoted to implementing a faculty development program (the GPC Training Program) through which twenty faculty teams from around the country were trained. Twelve of the 20 (60%) faculty teams provided evaluation data to the external evaluation team. Sixty-five of 99 (66%) of the individual faculty team participants provided evaluation information through the final questionnaire.

The 12 teams who provided external evaluation data reported conducting a total of 16 (range 1-5) faculty development efforts. A total of 859 participants were trained through these 16 events across 12 programs, for an average of 71 participants per program. Types of faculty development activities ranged from noon conferences to half-day faculty workshops and retreats. Some used standardized patients and had developed Websites to deliver information, reinforce, and provide resources to faculty on genetics in primary care education. Clinical faculty were present in the faculty development efforts at these 12 programs. Over 50% of these institutions also had clerkship and course directors and department chairs present at the faculty development sessions. In 14% of these institutions, deans participated in the faculty development activities. Eighty-five percent of GPC faculty team respondents (66% response overall) reported being adequately to very well-prepared to incorporate clinical application of genetic information into undergraduate and graduate primary care education. Over half of the respondents rated their ability as excellent to good at incorporating faculty development and genetics principles into their teaching. These data suggest progress toward accomplishment of GPC's initial goal to enhance the ability of faculty to incorporate the clinical application of genetic information into primary care medical education.

Continued work in Phase II was made possible through a contract modification at the end of the third year which allowed workgroups to undertake collaborative work in four key areas identified through the GPC Training Program as critical at the interface between genetics and primary care : 1) cultural competence; 2) family history taking; 3) red flags; and 4) evidence-based medicine. Through these workgroup efforts, various draft products for teaching were produced.

Phase III (the final 15 months of the project) was devoted to convening the workgroup leaders, receiving input from the Advisory Committee and final reporting. Three of the workgroups (cultural competence, red flags, family history taking) also undertook preparation of draft manuscripts during this period.

Conclusions

The GPC Project was organized around the concept of viewing genetics through a primary care lens. This concept was the impetus behind the leadership of the project coming through a primary care organization serving as the contractor and through primary care leaders in family medicine, general internal medicine and general pediatrics named as Project Director and Codirectors, respectively, of the project. In reflecting on this leadership focus five years following the inception of the GPC, it is clear that this organization made “in-roads” in helping to establish a national dialogue between primary care and genetics. The contract from HRSA mandated certain primary care specialties to lead the project. Future efforts in this area may benefit from looking at broader inclusion, to include OB-GYN.

By viewing genetics primarily through a primary care lens, much of what has been proven in genetics as directly impacting health outcomes was not emphasized in the GPC. Future examination of viewing genetics through a primary care lens would benefit from considering how to balance teaching around rare diseases where there is a wealth of knowledge in how genetics impacts health outcomes, versus common diseases seen in primary care, where much less knowledge is available concerning how health outcomes are impacted by genetics alone and/or genetics interacting with the environment.

In forming the Executive Committee with three primary care Codirectors, a geneticist educator with a Genetics Education Consultant Committee proved invaluable. Formation of the Advisory Committee was also critical. Leaders from primary care and genetics were joined with other organizational leaders in a large committee, with much expertise and many perspectives. The *Genetics for Primary Care Providers* course, held at the first meeting of the Executive and Advisory Committees launched the project in a highly interactive direction and rapidly identified issues which were to be at the core of the GPC Training Program.

Forming teams of faculty to develop and implement faculty development at their own sites was effective. The RFP requirement to have genetics expertise on each team was critical. It not only provided the needed genetics expertise, but also helped implement faculty development at home sites. Site visits to programs were conducted during the implementation period. This proved to be an effective method of informing both institutional leaders and GPC project leadership about the project and its impact.

Recommendations

Recommendations Regarding GPC's Approach to Faculty Development

The approach of bringing teams together to take training back to their own faculty on-site was effective. Using a case-based, interactive approach to teaching (as is fundamental to the teaching approach when cases are used), is recommended for engaging groups in the dialogue necessary to grapple with and effectively teach issues as complex as genetics in primary care.

The GPC produced many products for primary care faculty development in genetics (albeit many in draft form by the end of contract funding and still undergoing revisions) through an iterative process. Over the life of the GPC Project, this "hands-on" experience with using draft teaching products led to refinement of existing ones and identification of new areas where teaching products and materials were needed. Creating this kind of iterative process for development of teaching products for faculty development proved to be important in the GPC Project.

Being able to fully evaluate faculty development program implementation requires full participation in evaluation by those involved in the faculty development effort. Strategies to enhance fuller provision of data are important to consider in future projects.

Recommendations to the Funder

Collaboration among three federal funders was unique and highly successful with the GPC. By funding through the Health Resources and Services Administration, with cofunding from the National Institutes of Health and the Agency for Healthcare Research and Quality, the broad purview of primary care and genetics was reinforced both within funding agencies and for the broader medical education community.

HRSA now has a history of investing funds toward collaborative projects to help move primary care education forward. Consideration of the benefits and momentum generated through this kind of leveraging through a collaborative infrastructure should be given in the future as federal funds are directed toward primary care and genetics educational efforts.

The movement of project energy and creativity from faculty teams into workgroup efforts created synergy and tangible outcomes. Assuming availability of funds, dissemination of contract products should be a priority, in order to magnify impact of the federal investment in the project.

The rapidly changing nature of the knowledge base, clinical applications, information technology and policy environment for genetics in primary care presented a challenge for all concerned in this project. It will likely prove helpful in dynamic areas like this if, in the future, federal funders would plan specific opportunities to interlink and coordinate related and/or complimentary grants and contracts.

Recommendations to Primary care and Genetics Communities

A major accomplishment of GPC was the creation a group of academicians from primary care and genetics who have initiated and sustained (at least over the course of the GPC) a dialogue. Future programs drawing on this model of stimulating and sustaining a national dialogue are recommended.

The GPC was about marrying genetics with primary care. The GPC initiated a process of bringing primary care and genetics together in a meaningful way.

Five years after the GPC was launched, the purpose of the GPC, as articulated in the proposal to fund the contract, is as compelling as ever. The increasing importance of the work of the GPC and of genetics as primary care evolves toward the future cannot be understated. The importance of genetics factors in disease is important to emphasize in situations where there is a huge evidence base as well as in areas where there is far less evidence. A balanced approach in consideration of the evidence base in genetics is important to maintain as primary care and genetics continue to evolve.

MAIN TEXT

BACKGROUND AND INTRODUCTION

The Genetics in Primary Care (GPC): A Faculty Development Initiative has been conducted in three phases over five years (September 1998- December 2003) through a contract from the Maternal and Child Health Bureau (MCHB) of the Health Resources and Services Administration (HRSA) to the Society of Teachers of Family Medicine. Cofunding of the project was provided by the Bureau of Health Professions, HRSA, the National Human Genome Research Institute (NHGRI), National Institutes of Health, and the Agency for Healthcare Research and Quality (AHRQ).

The goal of the GPC Faculty Development Initiative was to enhance the ability of faculty to incorporate the clinical application of genetic information into undergraduate and graduate primary care medical education.

The GPC contract was awarded for three years (September 1998- September 2001). However, as subsequent needs were identified to fully implement the scope of work, the GPC contract was modified to extend the project by 27 more months. All delivered products, subcontracts, quarterly and other written reports, contract modifications, announcements, selection of faculty teams and consultants were approved by the Federal Project officer from the MCHB, HRSA. An overall timeline of the GPC Project is provided on the following page.

Phase I of the project, approximately the first 18 months, was devoted to organization, planning, and development. Formation of the Executive Committee with specific input from a Genetics Education Consultant Committee and formation of a larger Advisory Committee, representing 37 organizations, were key components of Phase I of work.

Phase II (approximately 2.5 years) was devoted to implementing a faculty development program (the GPC Training Program) which was developed by the Executive Committee and the Genetics Education Consultant Committee with significant input and involvement from the Advisory Committee. Continued work in Phase II was made possible through a contract modification at the end of the third year which allowed four workgroups to undertake collaborative work.

Phase III (the final 15 months of the project) was devoted to providing the opportunity for: 1) the four workgroup leaders to meet with the Executive Committee liaisons to the workgroups to consider designs of pilot studies of the draft products; 2) the Executive Committee to hold one final meeting with the Advisory Committee for purposes of obtaining input into the final report to the government; 3) workgroups to develop draft

manuscripts; and 4) the Executive Committee to complete contract reporting requirements.

GPC TIMELINE

❖ Phase I: Organization, Planning and Development

September 1998-June 2000

- Form Executive and Advisory Committees and Genetics Education Consultant Committee
- Identify Evaluation Consultant for the project
- Select an External Evaluator
- Develop a Master Plan to include a Program Outcomes Evaluation Plan

❖ Phase II: Implement Faculty Development Education and Training Projects

July 2000 – September 2001

- Select faculty teams (through national competitive process) to participate in GPC Training Program
- Hold Parts I and II of the GPC Training Program
- Implement faculty development activities at teams' programs/institutions
- Conduct site visits to faculty teams' programs/institutions
- Conduct external evaluation activities

October 2001-September 2002 (funding continued through Modification #4 to the contract)

- *Based on input received from the GPC faculty teams, site visitors, Advisory Committee, and external evaluation team, Phase II of implementation was extended until September 2002 to include continued collaborative work with the GPC faculty teams through four workgroups.*

❖ Phase III: Complete Evaluation and Make Recommendations to Funders

October 2002 – December 2003

- GPC External Evaluation Team complete final report on evaluation of the GPC Training Program
- GPC Workgroup Leaders and Executive Committee Liaisons meet to discuss design(s) of pilot study(ies) of products
- Hold final meeting of the GPC Executive and Advisory Committees to receive input from the Advisory Committee into recommendations for the final report on the GPC Project
- GPC Executive Committee complete GPC Project reporting requirements

ORGANIZATION OF THE MAIN TEXT

The Main Text of this final report is organized into the following sections:

	PAGE
PHASE I:	
<i>Project Organization</i>	13
<i>Approach to Evaluation and Selection of External Evaluation Team</i>	15
PHASE II:	
<i>GPC Training Program Design</i>	16
<i>GPC Training Program Implementation</i>	21
<i>GPC Training Program Outcomes</i>	28
<i>GPC Curriculum Revision (Sept 2001)</i>	29
<i>GPC Workgroup Product Development</i>	32
<i>GPC Dissemination Beyond Faculty Teams in GPC Training Program</i>	38
PHASE III:	
<i>Input from Advisory Committee on Recommendations and Final Reporting by the Executive Committee</i>	39
<i>Conclusions and Recommendations</i>	39
<i>Conclusions</i>	40
<i>Recommendations</i>	43
<i>Assessment of Degree of Success Achieved</i>	46
Attachments	
<i>Attachment 1: GPC Advisory Committee Organizations</i>	47
<i>Attachment 2: Listing of GPC Project Members 1998-2003</i>	49

PHASE I: Project Organization

Formation of the GPC Executive and Advisory Committees

An interdisciplinary Executive Committee (EC), codirected by a family physician, general internist, and general pediatrician, was named to lead the project. A geneticist educator, resident, medical student, project administrator, and project manager worked together with the three co-directors as members of the EC. The codirectorship from general internal medicine was provided by two leaders (serving consecutively), one serving from 1998-1999 and the second serving from 2000-2003.

An eleven-member Genetics Education Consultant Committee (GECC), under the direction of the geneticist educator member of the EC, brought to the Executive and Advisory Committees expertise pertinent to development of the GPC Training Program (i.e., contract Master Plan) in Phase I. Toward the end of Phase I, a curriculum specialist was hired to work with the Director of the GPC Training Program and Executive Committee to develop the training program.

Thirty-two (32) organizations were specified in the contract to be represented on the Advisory Committee. In October 1998, GPC Codirectors and the Project Manager and Administrator met with the Project Officer from HRSA's Maternal and Child Health Bureau and the Bureau of Health Professions representative to review plans for forming and organizing the Advisory Committee. Through consultation with the Project Officer and other federal funding agency representatives, 38 organizations were invited to submit two nominees, from which one would be chosen to represent that organization on the Advisory Committee.

Thirty-seven (37) of the 38 organizations approached (through written letters to Executive Directors) about representation on the GPC Advisory Committee responded positively with submission of one or more nominees. From this group of nominees, a subcommittee of Executive Committee members selected representatives for the GPC Advisory Committee with input from the Federal Project Officer and from the other two GPC Codirectors. Following approval by the Project Officer, an Advisory Committee of 37 members was formed. *Attachment 1*, page 47, contains a list of the 37 organizations represented on the Advisory Committee.

Additionally, three individuals were named as liaisons to the Advisory Committee representing the National Human Genome Research Institute (NHGRI), National

Coalition for Health Professional Education in Genetics (NCHPEG), the Agency for Healthcare Research and Quality (AHRQ), and the Centers for Disease Control and Prevention (CDC), with one of these individuals representing both NHGRI and NCHPEG.

Briefing for Cofunding Agency Representatives

A briefing with cofunding agency representatives was held in September 1999 in Rockville, Maryland. The three GPC Directors attended this briefing. Issues discussed at this briefing included formation of the Advisory Committee and the Genetics Education Consultant Committee, communication within the project and selection of an external evaluation team.

The following five levels of communication within the GPC, which had been identified by the Executive Committee at their February 1999 meeting, were discussed with cofunding agency representatives at the September 1999 briefing:

LEVEL I: WITHIN CONTRACTOR

At the level of the contractor, there was communication needed within the GPC Executive Committee (GPC EC) accomplished primarily through conference calls, electronic communication, and a GPC EC listserve. Summaries of EC conference calls were shared with the Project Officer.

Also at the level of the contractor, there was communication between the GPC EC and the GPC Advisory Committee (AC). At the first meeting of the GPC Advisory Committee, a communication plan was discussed, and a list-serve for the GPC EC and GPC AC was established soon thereafter. In addition to the GPC AC list-serve, circulation of project quarterly reports among Advisory Committee members, was a key element of the communication plan agreed to at the first meeting of the Advisory Committee.

LEVEL II: BETWEEN CONTRACTOR and SPONSOR (HRSA)

Communication between the contractor, primarily handled through the Executive Committee, and the sponsor, was handled largely through a GPCEXEC list-serve, electronic communication, and conference calls with the Project Officer from the MCHB and with the BHPR, HRSA funding agency representative.

LEVEL III: AMONG CONTRACTOR, SPONSOR, and TWO COFUNDERS

GPC Quarterly Reports were prepared in two parts: Part A: Content; and Part B: Technical. These reports were circulated among funding agency representatives from HRSA, NIH, and AHRQ. These reports were also circulated among members of the GPC EC and AC, including federal agency liaisons to the AC.

LEVEL IV: AMONG CONTRACTOR, SPONSOR, COFUNDERS, AND ORGANIZATIONS

Quarterly Reports were generated with two parts, one for content and one for technical aspects of contract compliance, so that representatives from federal funding agencies and from Advisory Committee organizations could use relevant parts of the quarterly reports to communicate with their own constituents about the progress of the project. When the GPC faculty teams joined the project, a broad GPC-GROUPS list-serve (comprised of GPC members who voluntarily joined) was established to facilitate communication more broadly. Over this list-serve, newsletters and announcements were disseminated.

LEVEL V: BETWEEN GPC PROJECT and THE MEDICAL EDUCATION COMMUNITY

The draft GPC curriculum was posted to a web site of MCHB educational products at the UTHSCSA in December 2001. Individuals interested in receiving information about this curriculum were informed of this posting so that they could access the draft curriculum. Additionally, many presentations at national meetings were conducted by members of the GPC EC, AC, GECC and faculty teams. These presentations were documented in a continually updated *Dissemination Activity Report*.

<p style="text-align: center;">Phase I: Approach to Evaluation and Selection of External Evaluation Team</p>
--

Members of the Executive Committee met during the first month of Phase I with the Project Officer and with the funding representative from the AHRQ. The purpose of this meeting was to share preliminary thoughts regarding evaluation of the GPC. Additionally, the GPC Executive Committee invited a medical education evaluation expert to serve as a consultant to the Executive and Advisory Committees on evaluation issues related to GPC.

At the initial meetings of the Project Officer and Project Codirectors, and in consultation with the evaluation consultant, it was agreed that the following points with regard to evaluation of the project were important. We needed formative and summative evaluation of GPC with funding of formative evaluation early on. Summative data would need to be collected to report outcomes and to generate information from which recommendations for future, continuing efforts could be made. It was agreed that the role of the external evaluator could be discussed at the first meeting of the Advisory Committee, with the director of the evaluation team participating in discussion of that role. It was agreed that funds required to conduct both formative and summative evaluation efforts would exceed the funds allocated for evaluation in the original contract budget, and that to begin to collect formative as well as baseline data, we needed to fund early on the project evaluation.

The GPC Executive Committee, in consultation with the Project Officer and HRSA representatives, developed and issued a *Request for Proposals* to identify an external evaluator for the GPC. This RFP was issued in June 1999 and circulated among Board Members and Faculty Development Special Interest Groups/Task Forces of: a) Ambulatory Pediatric Association; b) Society of General Internal Medicine; and c) Society of Teachers of Family Medicine. Additionally, it was circulated among Advisory Committee Members and national Project Team Leaders/Members of faculty development contracts awarded by the Division of Medicine and Dentistry, Bureau of Health Professions, HRSA to the Ambulatory Pediatric Association, the Association of Professors of Medicine –American Society of Internal Medicine, and the Society of Teachers of Family Medicine. Lastly, the RFP was circulated among external evaluators of other national initiatives and was placed onto the STFM web site.

Two proposals were received, and an outside review of the proposals was conducted. A panel of external reviewers representing family medicine, internal medicine, and pediatrics reviewed the proposals according to the review criteria specified in the RFP. The proposal submitted by a team from the Medical College of Wisconsin was selected following approval by the Project Officer. The Director of the evaluation team was notified of this selection just prior to the first meeting of the Executive and Advisory Committees so he could attend the meeting and receive preliminary input on evaluation.

PHASE II: GPC Training Program Design
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Defining GPC Content and the “Genetics for Primary Care Providers” Course

The Executive Committee determined that holding a seminar (later termed the “*Genetics for Primary Care Providers*” course) for the Advisory Committee at their first meeting would provide a common ground of understanding of content and issues to be addressed in a GPC faculty development program. At the first meeting of the Executive Committee in February 1999, a preliminary scheme for understanding the content to be covered through faculty development in GPC was discussed. Underpinning the thinking at that time was that training through the GPC would need to center on conditions selected according to prevalence in and applicability to primary care, and the ability to intervene and treat.

Review of Literature.

The following four content areas were identified by the GPC Executive Committee at their first meeting as a focal point for a review of the literature by the Genetics

Education Consultant Committee to help define content of a GPC faculty development program:

1. What do we need to teach primary care faculty in genetics? (centerpiece)
2. What is going on in undergraduate training in genetics?
3. What is going on in residency training in genetics?
4. What are the most appropriate faculty development methods?

A large amount of material related to existing curricula and educational programs in to genetics was also shared with the Project Manager by the Project Officer. These materials were catalogued and circulated among members of the Executive Committee. The Genetics Education Consultant Committee used the conceptual framework offered by the Executive Committee to review existing information. From this, they compiled a written report for the first meeting of the Executive and Advisory Committees.

Several issues and features were identified by the Executive Committee and Genetics Education Consultant Committees as important to the design of the *Genetics for Primary Care Providers* course. Content should be primary care friendly (primary care driven), case based and in adherence to the premise of acting when it makes a difference. We could not assume all Advisory Committee members would know background information on topics such as Fragile X, APOE4 and BRCA1/BRCA2 . Ethical, Legal, and Social Issues (ELSI) would also be of considerable interest to primary care (and we could not assume that all Advisory Committee members would have heard the term “ELSI”). The approach toward educating primary care physicians used in GPC was top down, meaning we were starting with the primary care perspective; this was important when one considers that 25% of family physicians practice in communities of less than 25,000 people. Newborn screening information would be perceived by pediatricians and family physicians as immediately useful.

From consideration of the above issues, take-away messages that were felt important for GPC learners to leave with included: 1) What can I do about this?; 2) What are the problems primary care physicians need to know or consider when acting?; and 3) What should primary care physicians avoid right now? To teach learners so that they could leave with these take away messages, it was felt that examples used in the training would need to illustrate when it would be reasonable to act and when not, and why.

How products emerging from GPC would be used by others is a question which could not be specifically answered early on. However, the thinking early on was that GPC educational products would be useful to other health professions education groups such as National Coalition for Health Professional Education in Genetics (NCHPEG).

The first meeting of the GPC Executive and Advisory Committees was held September 1999 in Bethesda, Maryland. The *Genetics for Primary Care Providers course*,

conducted at this meeting, was planned and implemented in accordance with the Essentials and Standards of the Accreditation Council for Continuing Medical Education through the joint sponsorship of the American Academy of Family Physicians and the Society of Teachers of Family Medicine.

Review of What is Currently Being Taught

Three individuals with oversight in their current professional capacities over national education of medical students and national training of residents in family medicine (Vice President for Education and Science, American Academy of Family Physicians), internal medicine (Senior Vice President of Education, American College of Physicians), and pediatrics (Director, Department of Education, American Academy of Pediatrics) were invited to participate in a panel discussion at the meeting on the topic of what is currently being taught about genetics to students and residents in family medicine, pediatrics, and internal medicine.

The GPC Project enlisted the services of a faculty development expert to provide assistance in gathering and presenting information concerning faculty development method for the first Advisory Committee meeting. Both this faculty development expert and the evaluation consultant participated in conference calls with Executive Committee in advance of the meeting to determine how best to plan the agenda to include discussing ideas on what works and what does not work in primary care faculty development at the meeting, in particular as it relates to the intended outcomes of GPC training. The Executive Committee worked to elucidate who the three levels of learners specified in the contract (i.e., clinical teacher, teacher/researcher/administrator, and leader) were and what training outcomes they hoped might be achieved for these learners through the GPC. This preliminary information was summarized and brought to the Advisory Committee meeting for discussion and further input.

Draft Design of the GPC Training Program

An initial draft of a GPC Training Program Plan (i.e., first draft of a Master Plan) was developed in January 2000 following a meeting of the Executive Committee in December 1999. The Draft GPC Training Program Plan reflected initial work performed by the GPC Executive Committee and Genetics Education Consultant Committee, with considerable input from the Advisory Committee through the *Genetics for Primary Care Providers* course.

A finalized draft of the GPC Training Program Plan (draft Master Plan) was prepared for review at a workshop held in conjunction with the second meeting of the GPC Executive and Advisory Committees in March 2000.

The goal of the March 2000 workshop was to determine:

1. Whether the proposed case examples provided an adequate range of topics for the first GPC training session;
2. What the core teaching points should be; and
3. What format was most useful in presenting these case examples at the training session.

The planning committee for this workshop was composed of several interested Advisory Committee members, Executive Committee members, consultants, the GPC Project Officer and the Federal Funding Agency Representative to the GPC from the National Human Genome Research Institute, NIH.

The draft GPC Training Program Design incorporated the following structural elements:

- A. Team approach.** GPC training focused on faculty teams of “exemplars,” consisting of family medicine (fm), general internal medicine (gim) and general pediatrics (gp) faculty targeted by the contract. This targeted membership within each team was to be supplemented with other faculty, as necessary, to enable faculty development activities by targeted fm, gim and gp faculty at home institutions.
- B. Team composition.** It was envisioned that each team would be composed of 3-5 members, consisting of at least three targeted faculty (fm, gim, gp). A geneticist faculty member was recommended (i.e., it was required that there be genetics expertise on the team). It was envisioned that a fifth member might be another targeted member or another faculty member who could facilitate faculty development activities at the home institution.
- C. Competitive selection of teams.** Applicant teams from residency programs and medical schools/colleges of osteopathic medicine competed for selection. Final selection of the participating teams was based in part on the aggregate representation of fm, gim, gp faculty across all teams and on aggregate representation of faculty who were primarily teachers, faculty who were teachers, researchers and/or administrators, and faculty who were leaders.
- D. Train the trainer model.** GPC faculty teams were expected to implement faculty development activities at home institutions as part of their participation in GPC training. To support teams in implementing faculty development at home institutions, the GPC training program was to incorporate the following features:
 1. Two training sessions spaced six months apart so that teams could apply what was learned at the first session back at home institutions;

2. Support through mentorship from GPC faculty during the six-month implementation period;
3. Faculty development at home institutions was to be based on needs assessments conducted by the faculty teams prior to attending the first training session;
4. Long-term tracking and evaluation of the individual teams' faculty development efforts, including plans to meet expectations of scholarly products of their work through presenting at national meetings or publishing;
5. The second training session was to focus on what was learned by individual teams and across teams, through evaluation findings from both the external evaluation of GPC as well as from evaluation by individual teams of their own efforts; and
6. The second training session was to provide a synthesis of what was learned and what might be generalizable.

E. Support for team participation. Each team selected to participate in the GPC Training Program was to receive a stipend (\$10,000) to support members' participation. Teams' travel to Parts I and II of the GPC Training Program was to be funded by the parent contract.

The following were key content features of the GPC Training Program:

1. Case-based curriculum

The GPC developed a curriculum to train faculty which was largely case based and interactive in nature. Additionally, the case-based format of the curriculum was intended to be helpful in elucidating the essential content and contextual issues at the core of the interface between primary care and genetics. This case-based methodology was piloted through the *Genetics for Primary Care Providers* course at the first meeting of the GPC Executive and Advisory Committees. A summary of points emerging from this course with regard to the interface between genetics and primary care and how that could be elucidated through case-based instructional methods was developed.

2. Curriculum intended to be adaptable to variety of teaching settings.

The intent was for the curriculum to be adaptable to a variety of teaching settings (i.e., to teach faculty responsible for educating students in clerkships or residency faculty responsible for training primary care residents).

3. Combined training with tracks.

Parts I and II included combined training for all team members coupled with specific training along three tracks. The tracks would focus on knowledge and skills of

particular interest to team members whose primary faculty responsibilities were that of a) clinical teacher, b) teacher/researcher/administrator, or c) leader.

4. *Focus on local resources.*

Teams were asked to identify local and regional resources as part of their application.

5. *Focus on use of existing genetics education resources.*

Teams were to become familiar with national resources as part of their participation in the training sessions. Hands-on instruction accessing resources via computers and the internet was incorporated into the training sessions.

6. *Learners as catalysts.*

Team members were encouraged to bring real questions from home learners (i.e., students and residents) into the training sessions as they developed concrete plans for faculty development activities in home institutions or programs.

Phase II: GPC Training Program Implementation
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Selection of Faculty Teams to participate in the GPC Training Program

In February 2000, an announcement concerning the upcoming GPC *Request for Proposals* to select faculty teams to participate in the GPC Training Program was issued. This announcement was drafted with input from the Advisory Committee.

The announcement was mailed/e-mailed to the following:

- 1) All GPC members, Executive Directors of GPC Advisory Committee Organizations
- 2) Board/Steering Committee Members of:
 - Ambulatory Pediatric Association
 - Society of General Internal Medicine
 - Society of Teachers of Family Medicine
 - American Society of Human Genetics
 - American College of Medical Genetics
- 3) Chairs of Departments of Family Medicine, Internal Medicine, and Pediatrics in schools of medicine and colleges of osteopathic medicine
- 4) Program Directors of residency programs in family medicine, internal medicine, and pediatrics, including osteopathic residency programs
- 5) Association of American Medical Colleges (AAMC) contact for the Council of Deans

- 6) Advisory Committee members of the Division of Medicine, Bureau of Health Professions, HRSA-funded faculty development contracts for family medicine, internal medicine, and pediatrics
- 7) All individuals who requested to be placed on the list to receive GPC announcements/newsletters.)

Representatives from 63 programs/institutions responded to this announcement by communicating interest in the GPC Training Program.

Issuance of Request for Proposals

The final *Request for Proposals* (RFP) (APPENDIX A) was based on the previously described structural and content elements of the draft GPC Training Program and was finalized immediately following the second meeting (March 2000) of the Executive and Advisory Committee. In April 2000 the RFP was mailed/e-mailed to the following:

1. All GPC Members (EC, AC, Consultants, External Evaluation Team Director, Evaluation Consultant, HRSA representatives, Federal Funding Agency Representatives)
2. Executive Directors of all GPC Advisory Committee organizations
3. Board members/Steering Committee members of:
 - Ambulatory Pediatric Association
 - Society of General Internal Medicine
 - Society of Teachers of Family Medicine
 - American Society of Human Genetics
 - American College of Medical Genetics
 - Association of Professors of Human Genetics
4. Chairs of Departments of Family Medicine
5. Chairs of Departments of Internal Medicine
6. Chairs of Departments of Pediatrics
7. Residency Directors in Family Medicine
8. Residency Directors in Internal Medicine
9. Residency Directors in Pediatrics

10. Contact for Council of Deans, AAMC

11. For osteopathic schools:

- Chairs of internal medicine, family medicine, and pediatrics departments
- Residency directors of osteopathic residency programs in internal medicine, family medicine, and pediatrics
- Deans of colleges of osteopathic medicine.

12. Advisory Committee members for the three faculty development contracts (one each for fm, im, and peds) funded by the Division of Medicine and Dentistry, Bureau of Health Professions, HRSA

13. MCHB contacts provided by the Project Officer

14. All other people who requested to receive the RFP (APPENDIX A) through the Project Manager.

Objectives of the GPC Training Program as outlined in the RFP were:

1. To increase the number of primary care (family medicine, general internal medicine, and general pediatrics) physician faculty in the United States who are trained to conduct faculty development and training activities in genetics in a culturally competent manner with other primary care faculty responsible for the education of medical students and training of primary care residents;
2. To train a mix of primary care (family medicine, general internal medicine, and general pediatrics) faculty, including faculty whose primary faculty responsibilities were clinical teacher, teacher/researcher/administrator, or leader;
3. To develop varying models for faculty development in genetics for primary care faculty which address various faculty whose roles are clinical teacher, teacher/researcher/administrator, or leader;
4. To develop a primary care faculty development curriculum in genetics which: a) is adaptable to a variety of teaching settings with primary care faculty responsible for educating medical students and/or training primary care residents; b) enables primary care faculty to teach content and concepts which are at the core of the contextual interface between genetics and primary care; and c) is attentive to issues of cultural and ethnic diversity.

Review of Proposals and Selection of Teams to Participate in the GPC Training Program

Fifty-three proposals were received by the June 1, 2000 deadline in response to the GPC RFP. Proposals were reviewed based on the team composition requirements and the review criteria in the RFP. As stated in the RFP, selection of teams was based on the outcome of the review and on consideration of aggregate characteristics across the teams, including a balance of family medicine, general internal medicine, and general pediatrics physician faculty team members, mix of faculty whose responsibilities are those of clinical teacher, teacher/administrator/researcher, and leader, geographic representation, and a variety of models. The Executive Committee met in June to select teams to recommend to the GPC Project Officer for funding. Included in this meeting by teleconference were the GPC Project Officer, and Federal Funding Agency Representatives from NIH and AHRQ.

Given the large response to the RFP, the Executive Committee and Project Officer discussed the ability to accommodate more than ten teams. It was agreed that twenty teams could be accommodated. The following twenty teams (listed alphabetically by the program/institution names) were selected to participate in the GPC training program:

Baylor College of Medicine
Boston University School of Medicine/Boston Medical Center
Cedars-Sinai Medical Center
Cook County Hospital/Rush Medical College
East Carolina University, Brody School of Medicine
Lancaster General Hospital Family Practice Residency Program
Mayo Clinic
Medical College of Wisconsin
New York Medical College
Palmetto Health Alliance/University of South Carolina School of Medicine
State University of New York School of Medicine at Buffalo
University of California, Los Angeles School of Medicine
University of Cincinnati College of Medicine
University of Florida College of Medicine
University of Maryland School of Medicine
University of Oklahoma Health Sciences Center – Tulsa
University of Utah Health Sciences/Primary Children's Medical Center
University of Vermont College of Medicine
University of Washington Family Practice Residency Network
Vanderbilt University Medical Center and Meharry Medical College

The Director of the External Evaluation Team oversaw inter-rater reliability studies. Following the June Executive Committee meeting, he reported that the results of the inter-rater reliability studies showed substantial evidence of concordance among reviewers and no evidence that there was substantial bias present beyond what would be expected by chance.

GPC Faculty Teams Queried Regarding Top Needs

Leaders of the twenty accepted teams were asked to submit the top three needs of their teams to the Executive Committee by August 1, 2000. The greatest area of need expressed by team leaders just prior to entering the GPC Training Program was related to curriculum resources, and educational resources for teaching genetics in primary care.

The following general and specific needs were reported by the team leaders:

General Needs

Resources/Content

- Curriculum resources/cases/templates/core material for primary care physicians
- Access to, development of educational resources including interactive internet resources, CD ROMs, standardized patients
- Genetic testing and genetic risk assessment and screening
- Emphasis on common problems with genetic ties (so that content is relevant to primary care precepting situations)
- Areas where medical schools are typically deficient in their teaching
- How to measure the extent of genetic diseases/conditions in own patient populations and existence of software for genograms
- Updated regional resource catalogue of who in the area can participate in primary care education around genetics

Curriculum Integration

- Institutional support/curriculum committee support for collaboration and investment
- Collaboration between primary care and genetics faculty
- Designing yearly curriculum and integrating over the 4 years of the medical school curriculum
- Integrating genetics with other areas of education such as ethics, clinical decision-making and communication skills
- Integrated plan to bring medical school efforts (basic and clinical sciences) and graduate education efforts together

Faculty Training Implementation and Evaluation

- Teaching/training methodologies appropriate for primary care teaching venues
- Motivating faculty for development/how to “advertise” and entice
- Evaluation strategies/tools available to use to know what we do makes a difference
- Peer-teaching methodology/tools and fundamentals of adult-learning applied to genetics
- How to teach screening

Specific Needs

GPC Curriculum Questions

- How to assess current knowledge and skills of faculty
- Information about the GPC curriculum – will teams have input into it?
- Help with identifying who the target population is – is it medical students, residents, community physicians, genetic counselors, licenses social workers, NP/PA students?

GPC Faculty Team Members’ Participation

- How much GPC faculty team members’ time is needed between the training sessions so they can “protect” faculty time

Collaboration among GPC Faculty Teams

- Coordination among teams to facilitate sharing
- Information systems to facilitate communication among teams

Conducting Parts I and II of the GPC Training Program

The GPC training program was a two-part train-the-trainer program to enhance the ability of primary care faculty to incorporate the clinical application of genetic information into undergraduate and graduate primary care medical education.

The dates for Parts I and II of the GPC Training Program were scheduled six months apart so as to allow faculty team participants time to implement faculty development activities at their home institutions between the two sessions. Parts I and II of the GPC Training Program were held October 10 - 12, 2000 in the Chicago, Illinois area and April 4-6, 2001 in the Washington, DC area, respectively.

GPC Faculty Trainers for the Training Program were identified from among interested members of the Genetics Education Consultant Committee and the Advisory Committee.

Objectives of the Part I of the GPC Training Program aimed to ensure that faculty team participants would be able to:

1. Understand and articulate the purpose of incorporating genetics into primary care teaching and practice;
2. Identify specific learning needs for home institutions regarding incorporating genetics into primary care teaching and practice;
3. Develop an implementation plan for addressing the learning needs at the home institution for the next 6 months;
4. Identify key Web-based and print resources for genetics;
5. Acquire teaching techniques to incorporate genetics into primary care teaching and practice;
6. Acquire teaching techniques and identify resources for addressing ethical, legal, and social implications of genetics in medicine.

Advisors from among the GPC Training Program faculty trainers were assigned to faculty teams to assist with development of faculty development implementation plans at Part I of the GPC Training Program. These implementation plans were revisited by advisors and their respective teams at Part II of the GPC Training Program.

Objectives of Part II of the GPC Training Program aimed at ensuring that faculty team participants would be able to:

1. Identify needs and opportunities for teaching genetics in primary care settings;
2. Demonstrate approaches to teaching genetics in primary care settings;
3. Identify strategies for creating buy-in at home institutions;
4. Share techniques for interdisciplinary work;
5. Participate in case-based discussions of genetics in primary care;
6. Develop revisions to the GPC curriculum;
7. Identify needs and next steps for continuing GPC work.

Site Visits to GPC Faculty Teams Between Parts I and II of the GPC Training Program

In between Parts I and II of the GPC Training Program, faculty teams began implementing faculty development activities and teams were visited by two members of the GPC Executive/Advisory/Genetics Education Consultant Committees. These site visits were conducted between February and April 2001. Site visit teams were formed from among volunteers within these committees with the intent of ensuring some

genetics and primary care expertise on each team. Each team had a primary and a secondary visitor. Wherever possible, the assigned advisor for each team visited that team's program/institution. In cases where the assigned advisor was visiting a team, that individual was designated as the primary visitor. In cases where it was not possible for an advisor to visit his/her assigned team, the primary visitor was a member of the Executive Committee, or if that was not possible, a member of the Advisory Committee. Where it was not possible for the advisor to visit his/her team, the primary site visitor was encouraged to make contact with the assigned advisor in advance of making the visit. Federal representatives from HRSA, NIH, and AHRQ were notified of the opportunity to accompany site visit teams. Site visitors reported back to the GPC Project Manager following the visits. In addition, the Project Manager conducted organizational teleconferences with visitors prior to making visits.

These visits were structured so as to be of assistance to teams and informational for the visitors. Visiting teams were comprised of two GPC Executive, Advisory or Genetics Education Consultant Committee members, one assigned as primary visitor and the other as secondary visitor (in one instance, travel delays caused one visitor to cancel). Each visiting team possessed both primary care and genetics expertise. Institutional leaders were encouraged to participate in the site visits. The agendas for the visits were developed collaboratively by GPC faculty team leaders and primary site visitors. The site visits were between 4-8 hours in length and each visitor made between one and four site visits (eleven visitors made one; nine visitors made two visits; two visitors made three visits, and one visitor made four visits).

A total of 23 members of the GPC Executive/Advisory and Genetics Education Consultant Education Committee participated as site visitors. Fourteen Advisory Committee members, 4 Executive Committee members (Project Director, two Codirectors and Geneticist Educator) and 5 Genetics Education Consultant Committee members conducted the visits.

More summary information concerning the site visit findings can be found in APPENDIX B.

Phase II: GPC Training Program Outcomes
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Evaluation activities clustered around two GPC Training Program components: 1) Parts I and II of the GPC Training Program conducted off site for faculty teams; and 2) the on-site local implementation of faculty development by teams. A combination of workshop evaluation forms and forms aimed at assessing features of faculty development activities conducted by teams at their home institutions were utilized. A final evaluation questionnaire mailed to all faculty team participants following completion of the GPC

Training Program was used for reporting on institutional support and impact of the GPC Training Program and on team members' knowledge of genetic and faculty development principles, and their ability to provide genetics-focused faculty development

Twelve of the 20 (60%) faculty teams provided evaluation data to the external evaluation team. Sixty-five of 99 (66%) of the individual faculty team participants provided evaluation information through the final questionnaire.

At the time of the site visits, prior to the second part of the GPC Training Program, 12 of the faculty teams reported that at least one faculty development activity had been implemented on site. Following the second part of the GPC Training Program 12 faculty teams provided evaluation data to the external evaluation team relative to faculty development activities conducted on site. These 12 programs reported conducting a total of 16 (range 1-5) faculty development efforts. A total of 859 participants were trained through these 16 events across 12 programs, for an average of 71 participants per program. Types of faculty development activities ranged from noon conferences to half-day faculty workshops and retreats. Some used standardized patients and had developed Websites to deliver information, reinforce, and provide resources to faculty on genetics in primary care education. Clinical faculty were present in the faculty development efforts at these 12 programs. Over 50% of these institutions also had clerkship and course directors and department chairs present at the faculty development sessions. In 14% of these institutions, deans participated in the faculty development activities.

Eighty-five percent of GPC faculty team respondents (66% response overall) reported being adequately to very well-prepared to incorporate clinical application of genetic information into undergraduate and graduate primary care education. Over half of the respondents rated their ability as excellent to good at incorporating faculty development and genetics principles into their teaching. These data suggest progress toward accomplishment of GPC's initial goal to enhance the ability of faculty to incorporate the clinical application of genetic information into primary care medical education.

A copy of the full report from the external evaluation team can be found in APPENDIX C.

Phase II: GPC Curriculum Revision (September 2001)

At Part II of the GPC Training Program in April 2001, input was received concerning updates to the GPC Curriculum. Following this session, further input was sought by

obtaining reviews from volunteer GPC members on all of the GPC modules within the curriculum. The information from these reviews was used to revise the curriculum by September 30, 2001.

The GPC Curriculum (September 2001 revision) was placed onto the public Website at University of Texas Health Sciences Center in San Antonio, where the Maternal and Child Health Bureau, HRSA houses educational materials. An announcement about the curriculum being placed there was sent via e-mail in December 2001 to all individuals who had inquired publicly about the GPC Project and its materials through the Project Manager.

The materials in the September 2001 GPC Curriculum were designed to serve as a bridge between genetics and primary care. They were not intended as a freestanding curriculum. Each module cites Web-sites for additional background information and articles from the medical literature, including relevant consensus and policy statements where applicable. The modules (listed on the following page) provide a series of teaching cases, developed, with the aim to be representative of patients seen in primary care, while also allowing for the demonstration of genetics issues and principles. The cases are intended to serve as the models for engaging medical students' and residents' interest in genetics topics. For each case, questions are noted and a brief discussion is provided. The additional Websites and other references listed provide the basis for more in-depth exploration of each topic. The eight topics chosen for development of teaching cases are taken from core areas of primary care practice. These teaching modules were used in the GPC Training Program. They were also reviewed by experts in primary care and genetics for relevance and accuracy.

Modules in the September 2001 revised GPC Curriculum addressed the topics of:

- Breast and Ovarian Cancer
- Cardiovascular Disease
- Colorectal Cancer
- Congenital Hearing Loss
- Dementia
- Developmental Delay
- Iron Overload
- Ethical, Legal, and Social Issues (ELSI)

The September 2001 GPC Curriculum revision is currently available at:

http://genes-r-us.uthscsa.edu/resources/genetics/primary_care.htm

There were a number of additional innovative curricular innovations being conducted at faculty team institutions which were learned about through the site visits and through discussions at Part II of the GPC Training Program. These innovations included:

- Development of a model multi-media CD-ROM presenting a variety of different educational media relevant to GPC teaching on a specific case (allowing primary care faculty to select what will be most useful to them for their teaching needs and style)
- Trial applications of “Audience Response System” technology in OB-GYN conferences on prenatal genetic testing
- Development of “Genetic Moments” ads for workshop to be projected before internal medicine Grand Rounds
- Sessions for Pediatrics neighborhood health center based faculty
- "Gene-O-Gram" emailed, 1-minute CME
- Web portals in each precepting setting.
- Consideration of redesigning medical records to include prompt for family history and pedigree diagram
- Simulated patients Objective Structured Clinical Examination (OSCE) and Objective Structured Teaching Examination (OSTE), web based instruction and genetics web site
- Genogram overlay of pedigree
- Provision of routine Email messages highlighting some interesting, pertinent, CONCISE, genetics issue
- Trigger tapes to start discussions
- Genetic counseling students as co-facilitators
- Web-based genetics resources site
- Family history questionnaire
- “Kick-off” slide presentation which is a good overview of the importance of genetics

- Inpatient teaching rounds for primary care disciplines utilizing a physician geneticist and a clinical medical genetic counselor
- Use of already established conference times in the different primary care departments (e.g.: Journal Clubs, Clinic Conferences, etc)
- Use of standardized patients throughout the course (not just during testing) with the “time in and time out” approach which allows students to “freeze” their interview in time and request feedback and suggestions
- Problem based learning cases
- “Genetics Week” as a catalyst for the whole campus to get a boost of interest in genetics
- Combined genetics and non-genetics teaching cases in teaching which underscores the integration of genetics into primary care
- Scripting of shared decision-making which provides a powerful teaching message

<p style="text-align: center;">Phase II: GPC Workgroup Product Development</p>
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Based on several sources of input (feedback received in April 2001 from the GPC teams at Part II of the GPC Training Program, input received at the fourth (April 2001) GPC Advisory Committee meeting, the summary of reports from GPC site visitors, and the GPC external evaluation team’s executive summary of their evaluation of Part II of the GPC Training Session) there was an expressed need for teams to collaborate around production of curricular tools and products which would enhance each team’s own productivity and be of potential benefit nationally.

The contract was modified in September 2001 to meet this need. The purpose of this modification was to augment faculty development activities at teams’ home institutions through pooling of team members’ efforts and expertise. It was anticipated that this pooling of GPC team and Advisory Committee efforts and expertise would yield superior products which would enhance faculty development efforts at GPC teams’ institutions and would provide curricular products for eventual national dissemination.

Maintaining collaboration, communication, and the dialogue initiated through the GPC Initiative was an important principle behind continuation of the GPC through this

modification. The strategy of forming workgroups with representation from multiple GPC faculty teams and the Advisory Committee members was envisioned to ensure that collaboration and communication, with this necessary expertise, would continue on as broad a level as possible. The role of the Executive Committee liaisons to the four workgroups was created to help ensure cross-workgroup interaction.

The four content areas addressed by the workgroups were:

- Family History Taking
- Red Flags
- Cultural Competence
- Evidence-based Medicine

One technical change in how work was to be carried out was that the private GPC Website was to be transferred from its then current Genetests location to the MCHB, HRSA educational materials site at the University of Texas Health Sciences Center at San Antonio. This transfer was completed by late Spring 2002.

For the purposes of maintaining this cross-workgroup interaction while at the same time allowing workgroups to pursue their own work, two administrative mechanisms for work to be performed through this contract modification were established: 1) meeting of the workgroups; and 2) workgroup Websites and list-serves.

Collaborative Workgroup Meeting Feb 21-22, 2002

In order for all workgroups to understand the definition of their own products and how they may overlap with products to be developed by other workgroups, it was important to hold a meeting of all workgroups early enough in the process so as to facilitate ongoing interaction where necessary. For example, it had already been suggested that there were likely to be areas of overlap between the content of the Red Flags and Family History Taking Workgroups. Similarly, the content of the Cultural Competence Workgroup was likely to have potential overlap with areas addressed by the other three workgroups.

The purpose of the collaborative workgroup meeting was to inform all workgroups about the products to be developed within each workgroup, to share information and resources pertinent to the work of all groups, to allow workgroups some individual face-to-face meeting time, to identify collaboratively where the most important areas of overlap were likely to occur, and to determine how areas of overlap could best be addressed in developing the four workgroups' products.

All Advisory Committee workgroup leaders, Advisory Committee workgroup members, and two faculty team workgroup members from each of the twenty faculty teams, were invited to attend this meeting. Genetics Education Consultant Committee members who were participating in a workgroup were also invited to attend this meeting. Additionally, the Executive Committee liaisons, the Project Manager, Project Assistant and Project Administrator, government representatives, GPC Curriculum Specialist, and Director of the External Evaluation Team (who served as consultant to workgroups around pilot study design issues during this phase of the project) participated.

Following the February 2002 meeting of the GPC workgroups, each of the four workgroups undertook development of draft products. A combination of conference calls and electronic mail methods were used by each workgroup to accomplish its work. By the time of the Spring 2002 meetings of the Society of Teachers of Family Medicine, the Society of General Internal Medicine, and the Pediatric Academic Societies, the workgroups had formulated plans for specific products. Summaries of each workgroup's plans were prepared and circulated via GPC presentations at these three Spring meetings. Following these Spring 2002 meetings, considerably more work took place within workgroups to complete draft products.

Between June 17 and July 12, 2002, completed draft products from each of the workgroups were posted to the GPC internal web site at the MCHB's site at UTHSCSA by the Project Manager. Advisory Committee members, Executive Committee members, workgroup members, and GPC team members who were not on the workgroups but who were members of the GPC Groups list-serve were notified of the site address, how to access it, and of the products being posted for voluntary review.

A complete set of draft workgroup products, workgroup members and the Plan for the work of the workgroups is appended to this report in APPENDIX D.

The draft workgroup products can be accessed at the internal GPC Web site:

Genes-r-us/gpc/gpc/

Username: gpcgroup Password: member

Overview of Family History Taking Workgroup Products

Family History Tool Kit

Introduction and questions for the initial posting

The goal of the GPC Family History Working group was to create an instrument that could be easily used by primary care physicians to obtain a reliable family history that targeted common and important genetic and familial disease. The group wanted to

suggest a tool that was brief and simple to use, yet comprehensive and flexible to the patient's and physician's needs.

The characteristics sought in this tool included several characteristics:

- Targeted to common conditions (informed by above, geography, etc)
- Adaptable to multiple formats
- Provides a staged algorithm that screens and expands
- Addresses informed consent/confidentiality
- Elicits specific patient concerns
- Brief
- Simple
- Patient administered (can be)
- Includes decision-support function
- Prioritized by possible intervention/potential impact
- Prompts physician by key life events to review family history
- Updatable
- Delineates Family composition
- Includes personal family names (or has that option)
- Includes Ethnicity
- Addresses Adoption
- Collects important non-genetic family factors

We could not envision one tool that could do all these things. So we present a tool kit of options for the physician.

The family history tool kit consists of three parts.

1. The mnemonic "SCREEN"
2. The Family History Instrument, Parts 1, 2, 3
3. The Second Tier Questions

The SCREEN Mnemonic

The purpose of the SCREEN mnemonic is to provide an easy way for clinicians to "screen" for genetic disease. SCREEN directs the patient's attention to their family history in four ways. The SC or some concerns part of the SCREEN is asked as an open-ended question to allow patients to express any concerns that they may have. After starting with a broad assessment, the R of SCREEN reminds the clinician to ask about Reproduction. The first E is for early and allows the clinician to focus the patient on any early disease, death, or disability. For purposes of this mnemonic, early is defined as less than 60 years old, except for the generally accepted guideline for cardiac disease, where early is 55 years for men and 65 years for women. Early may also uncover childhood or adolescent disease that was not elicited by the reproduction

question. The second E is for ethnicity. The family history group has included specific groups to ask about as second tier questions. The mnemonic suggests two ways to elicit information about ethnicity. The last part of SCREEN is for the non-genetic or not necessarily genetic conditions that may occur in families. This is to remind the practitioner that multigenerational risk may be due to environmental or social issues.

The Family History

The Family History tools are a collection of three forms that can be used individually or together.

Part I. Family Disease Checklist

Part II. Family Medical History

Part III. Graphic Family History/Genogram/Pedigree

Each Part (form) adds to the family history in a different way. Part I and/or Part II should (optimally) be completed by the patient prior to the visit. They could be provided in the waiting room, sent to the patient at home to complete, or available on a practice website. Part III is the graphic family history/genogram/pedigree instrument. The physician or practitioner would construct the family history based on information obtained from Part I and/or Part II. On the back of the graphic family history is a risk stratification scheme, to allow the physician to list and discuss potential familial risk.

Overview of the Red Flags Workgroup Products

The GPC Red Flags Workgroup developed the mnemonic Family GENES for organizing a primary care physician's thinking around red flags for genetics in primary care.

This Family GENES mnemonic is described in one stand-alone draft product/tool.

This mnemonic Family GENES has also been incorporated into RED FLAGS BOXES which have been developed as draft revisions for several of the Sept 2001 GPC Curriculum modules. Specifically, stand-alone Red Flags Boxes most with references, have been developed as draft revisions for the following modules in the Sept 2001 GPC Curriculum:

- a. Developmental delay
- b. Cardiovascular disease
- c. Colorectal cancer
- d. Iron overload
- e. Congenital hearing loss
- f. Dementia

g. Breast and ovarian Cancer

The Red Flags Workgroup developed two versions (primarily formatting differences) of an indications for genetic referrals table which are combined into one document for review purposes. The workgroup would like input on which version is preferred (see below re: questions this workgroup is asking reviewers to think about).

Additionally, the group developed two substantial revisions to the congenital hearing loss module in the Sept 2001 GPC Curriculum. One was an algorithm for Congenital Hearing Assessment using an AABR (sheet 1) and an EOAE (sheet 2), and the second was an additive revision to the Congenital Hearing Screening Module.

Overview of the Cultural Competence Workgroup Products

The products of the GPC Cultural Competency Working Group include:

1. a separate module titled, The Cultural Implications of Genetic Information;
2. creation of the PRACTICE model for thinking about cultural issues in the delivery of genetics in a primary care (see case #2 in the module, The Cultural Implications of Genetic Information);
3. revisions of seven GPC modules as posted to the public Website in December 2001 with attention to issues of cultural competency (breast cancer, colorectal cancer, dementia, cardiovascular disease, hemochromatosis, developmental delay, congenital hearing loss)

The workgroup members revised the September 2001 GPC curriculum modules using two approaches. We developed text that could be added to the existing cases with additional learning objectives, and we illustrated how the PRACTICE model could help someone in primary care think through the core elements of cultural competency in the delivery of genetic services.

Overview of the Evidence-based Medicine Workgroup Products

Introduction to DRAFT Evidence-based Medicine Workgroup Products

The GPC Evidence-Based workgroup envisioned a Website linked to other sites. Draft products developed toward this end included a draft word document as a suggestion for a Webpage entitled "How to Utilize these Materials". This draft included links where available on the Internet. Other links were specified as possible in the draft but it was not feasible to portray these in a text document. Introduction to the Web page included a draft review of available websites which would serve as useful linkages to the

anticipated web site. Additionally, the group produced an addition to the 2001 GPC curriculum modules on the topic of Fragile X Syndrome.

Reviews of Workgroup Products

In August 2002, it was decided to have workgroups review products of another assigned workgroup and to have Executive Committee members review assigned products. Tab E contains a copy of the written reviews received. The nature of the bulk of the reviews received indicated that: 1) overall, the workgroups had achieved a great deal in a short amount of time; and 2) meaningful revisions to workgroup products developed within this short timeframe was beyond the timeframe and resources available through this contract modification.

Workgroup Resource Document

To aid the workgroups in their work, attendees of the February 2002 workgroup meeting brought resources to the meeting to share with other participants. The various citations for these resources were compiled by the Project Manager. During the process of developing their products, workgroups came across additional resources which they felt were important to add to the list of resources. This process of adding to the supplemental resource list continued through until the end of September. The final compilation of supplemental resources generated by the four workgroups was posted to the internal GPC site and can be found at the end of the workgroup products in APPENDIX D.

Phase II: Dissemination Beyond Faculty Teams in GPC Training Program

Dissemination of lessons learned through the GPC Project through various interactive sessions and exhibits at national meetings was an area of activity over the life of the project.

Overall, there were 24 interactive presentations to national medical education audiences concerning the GPC Training Program, the curriculum and workgroup products (there was one additional precourse which drew on the September 2001 GPC Curriculum as a resource) and 19 exhibits, including one international exhibit. Through these activities a number of faculty nationwide were reached. Reaching these faculty nationwide with training from the GPC project, provided a level of faculty development impact which was in addition to that realized through training of the twenty faculty teams.

Aside from support for materials and exhibit development, many of these dissemination activities were conducted voluntarily by GPC members.

A copy of the updated (9/03) GPC *Dissemination Activity Report* can be found in APPENDIX E.

Phase III: Input from Advisory Committee on Recommendations and Final Reporting by the Executive Committee

MODIFICATION #6 TO THE CONTRACT

The STFM contract was extended from October 2002-September 2003 for the purposes of a) the Workgroup Leaders and Executive Committee liaisons reviewing all of the workgroup products and designing a pilot study(ies) of the workgroup product(s); b) Executive Committee receiving input from the Advisory Committee regarding recommendations for the final report; and c) final reporting activities undertaken by the Executive Committee.

A meeting of the GPC Workgroup Leaders and Executive Committee Liaisons was held January 11, 2003 to review the workgroup products and discuss pilot study design. A conference call was held February 24, 2003 among members of the GPC Executive Committee and Project Officer to discuss the outcomes of the January meeting.

MODIFICATION #7 TO THE CONTRACT

Through a final modification (#7) to the contract, the period of performance was extended, at no added cost to the government, by three months, from September – December 2003. This allowed the Executive Committee to convene a final meeting of the Advisory Committee for purposes of providing input into recommendations and the draft final report. It also allowed for interested workgroups to devote time and resources to development of draft manuscripts.

PHASE III: CONCLUSIONS AND RECOMMENDATIONS

The following conclusions and recommendations are derived from an examination of: 1) the organization and implementation phases (Phase I and II) of the GPC Project; 2) the final report from the External Evaluation Team, in particular pages 41-42 of that report which address their recommendations; and 3) consideration of input received from the GPC Advisory Committee at the final meeting of the GPC Executive and Advisory Committees held on October 20, 2003. Prior to that meeting a draft final report was

circulated among all GPC Executive and Advisory Committee members, and Genetics Education Consultant Committee members. Then, on site at the meeting, a draft set of conclusions and recommendations to the final report was specifically discussed. Incorporated into the written summary of that meeting was input into the draft report which was received by Advisory Committee members who were unable to attend the meeting.

Conclusions

Phase I: Project Organization

The GPC Project was organized around the concept of viewing genetics through a primary care lens. This concept was the impetus behind the leadership of the project coming through a primary care organization serving as the contractor and through primary care leaders in family medicine, general internal medicine and general pediatrics named as Project Director and Codirectors, respectively, of the project. In reflecting on this leadership focus five years following the inception of the GPC, it is clear that this organization made “in-roads” in helping to establish a national dialogue between primary care and genetics.

As the Advisory Committee reflected at their last meeting in October 2003 on how the GPC Project was organized, there were two issues which arose as important to consider in the future. The first was for future inclusion of OB-GYN as a specialty critically involved in genetics and the future of healthcare in this country. The contract from HRSA mandated certain primary care specialties to lead the project. Future efforts in this area may benefit from looking at broader inclusion, to include OB-GYN. Secondly, by viewing genetics primarily through a primary care lens, much of what has been proven in genetics as directly impacting health outcomes was not emphasized. Future examination of viewing genetics through a primary care lens would benefit from considering how to balance teaching around rare diseases where there is a wealth of knowledge in how genetics impacts health outcomes, versus common diseases seen in primary care, where much less knowledge is available concerning how health outcomes are impacted by genetics alone and/or genetics interacting with the environment.

In forming the Executive Committee, codirectorship by primary care leaders in family medicine, general internal medicine, and general pediatrics was critical. Combining this leadership with a geneticist educator member of the Executive Committee and a Genetics Education Consultant Committee proved invaluable to bringing the optimum genetics and primary care medical education expertise to bear on elucidating the content and a viable approach to the faculty development program of the GPC.

Formation of the Advisory Committee was also critical. Leaders from primary care and genetics were joined with other organizational leaders in a large committee, with much expertise and many perspectives. By including a broad range of 37 organizations represented, the many viewpoints and constituent audiences were reflected in the ongoing discussions and invaluable advice and input from this committee to the Executive Committee in carrying out the project.

The Executive Committee decided early on that the approach to the first Advisory Committee meeting should provide the opportunity to examine issues at the interface between genetics and primary care. The *Genetics for Primary Care Providers* course, held at the first meeting of the Executive and Advisory Committees in September 1999, launched the project in a highly interactive direction and rapidly identified issues which were to be at the core of the GPC Training Program. The Genetics Education Consultant Committee identified a case-based approach as key to bringing out the necessary content and critical issues at the interface between genetics and primary care. This approach to conducting the *Genetics for Primary Care Providers* course initiated an intensive dialogue between the primary care and geneticist members of the Advisory Committee. Some of the cross-cultural issues with regard to genetics and medicine, both historically and present today, were elucidated through this dialogue in a profound way, with some Advisory Committee members commenting that it was a kind of “cross-cultural experience” itself. This dialogue between genetics and primary care on cross-cultural and many other issues initiated through this first meeting of the GPC Advisory Committee is still continuing to progress four years later.

Phase 2: Project Implementation

Forming teams of faculty to develop and implement faculty development at their own sites was effective. Although one person within each team often proved to be the “champion” of the effort, having others to draw on was important to achieving maximum potential impact within complex institutions. Additionally, by requiring teams to be comprised of between 3-5 members, teams were able to identify primary care and geneticist colleagues within their own institution who had varying areas of expertise to carry out teaching and faculty development around genetics.

The RFP requirement to have genetics expertise on each team was critical. It not only provided the needed genetics expertise, but also helped implement faculty development at home sites. One unanticipated outcome of this requirement was that the geneticist team members learned about and developed an interest in primary care. A group of geneticists came together informally during the latter part of Phase II to explore these issues electronically.

Site visits to programs were conducted during the implementation period. This proved to be an effective method of helping to inform the Executive and Advisory Committees about issues experienced on site. Site visits also proved to be helpful to the teams in communicating with institutional leaders about the project.

The external evaluation report states (page 41) “many faculty members’ comments conveyed that they were getting much of the ‘what’ to teach but not the ‘how’ to teach”. Parts I and II of the GPC Training Program were highly intensive and could not provide all of the necessary background regarding content and faculty development expertise. Requiring that teams have faculty development expertise was one mechanism to ensure that teams had adequate skills in conducting faculty development. However, given the complexity of issues regarding genetics and primary care, more time devoted to faculty development skills might have been warranted.

Six months was not long enough for all twenty programs to implement faculty development programs at their home institutions. At the time of the site visits (conducted 4-6 months into the implementation period), twelve teams had completed at least one faculty development session. One might argue that the period for implementation should have been longer. The External Evaluation Team concludes in its final report (page 41) that “evaluation data indicated that faculty members were more prepared to implement faculty development activities after the second workshop than after the first.” One lesson from an adult learning perspective, however, is that by having a short implementation period, we created a “need to know” which drove faculty to want to learn more. From this perspective, the shorter timeframe for implementation may not, therefore, have been an impediment but part of an entirely appropriate process of faculty development. One lesson may be more clear, however, and that is that six months may be too short a timeframe to create curricular change within institutions.

Advisors were assigned to teams at Part I of the GPC Training Program to help teams complete program implementation plans. Advisors met again with assigned teams at Part II of the GPC Training Program to review progress on implementation of the plans (attempts were also made to assign advisors as site visitors). Assignment of advisors proved to be useful to some teams but not to all. It is possible that there was not enough time within the GPC Training Program sessions to devote to building an “advisor-advisee” relationship. In other cases, teams had articulated needs early and an advisor was in a position to help address these needs. It is also true that some teams were more prepared at the outset to implement faculty development for primary care faculty in genetics than others. The readiness of teams within their own institutional structures and within the faculty development directions already in place at the time of the GPC varied considerably. Therefore, the role of an Advisor to programs varied depending on a combination of the match between the advisor’s expertise and the

team's need, and the overall readiness of the team to implement faculty development in genetics within their institutions.

Recommendations

Recommendations Regarding GPC's Approach to Faculty Development

1. The approach of bringing teams together to take training back to their own faculty on-site was effective. Requiring representation from primary care and genetics expertise is recommended for future programs with similar aims. Using a case-based, interactive approach to teaching (as is fundamental to the teaching approach when cases are used), is recommended for engaging groups in the dialogue necessary to grapple with and effectively teach issues as complex as genetics in primary care.
2. The GPC Training Program might have provided more needs assessment and evaluation tools for teams to evaluate their own training efforts. Although this was addressed via a simple needs assessment activity prior to Part I of the GPC Training Program, more attention to providing tools to faculty teams for needs assessment and evaluation in future programs is recommended. How teams would use needs assessment tools, however, would vary according to what is already being taught with regard to genetics in primary care at a given institution. So, teams are bound to have differing needs for needs assessment tools and would use tools in different manners.
3. The GPC produced many products for primary care faculty development in genetics (albeit many in draft form by the end of contract funding and still undergoing revisions) through an iterative process. A draft case-based curriculum was taken to the *Genetics for Primary Care Providers* course and was then revised for the GPC Training Program. Following the GPC Training program the GPC curriculum was further revised, reflecting many levels of input and piloting. Emerging from the work of the GPC Executive and Advisory Committees with the faculty teams in using the GPC Curriculum, four content areas arose as important to explore further: cultural competence, family history taking, red flags and evidence-based medicine. Workgroups were formed to develop draft products around these four critical issues at the interface between genetics and primary care. Over the life of the GPC Project, this "hands-on" experience with using draft teaching products led to refinement of existing ones and identification of new areas where teaching products and materials were needed. Creating this kind of iterative process for development of teaching products for faculty development proved to be important in the GPC Project.
4. Being able to fully evaluate faculty development program implementation requires full participation in evaluation by those involved in the faculty development effort. Twelve of the twenty faculty development teams funded through the GPC Project

provided evaluation data to the External Evaluation Team. As part of the application, teams were asked to sign a statement of their intention to provide data as requested by the external evaluation team. The Executive Committee might have tied payment of stipend directly to receipt of full evaluation data as one mechanism to ensure that all twenty teams provided data as requested by the External Evaluation Team.

Recommendations to the Funder

1. Collaboration among three federal funders was unique and highly successful with the GPC. By funding through the Health Resources and Services Administration, with cofunding from the National Institutes of Health and the Agency for Healthcare Research and Quality, the broad purview of primary care and genetics was reinforced both within funding agencies and for the broader medical education community.
2. HRSA now has a history of investing funds toward collaborative projects to help move primary care education forward. These are expensive projects due to the large amount of funding required to support the collaborative infrastructure relative to the amount given to institutions. The GPC was another example of a collaborative project with a large infrastructure, which successfully leveraged funding (in relatively small amounts) to move primary care into the future. Consideration of the benefits and momentum generated through this kind of leveraging through a collaborative infrastructure should be given in the future as federal funds are directed toward primary care and genetics educational efforts.
3. The movement of project energy and creativity from faculty teams into workgroup efforts created synergy and tangible outcomes. The funder's willingness to modify the contract to fund this component was responsive. This level of responsiveness by the funder to learning and modifying during the course of a contract is highly recommended. The external evaluation ended with evaluation of the GPC Training Program and ideally might have continued through this phase of workgroup activity.
4. Assuming availability of funds, dissemination of contract products should be a priority, in order to magnify impact of the federal investment in the project. At the conclusion of the project, electronic and web-based communication to appropriate constituents will widely inform the availability of contract products.

Pending the availability of funds, a follow up to the contract could include important dissemination of contract products and findings through an international conference on the integration of rapidly evolving genetic information into the education of primary care clinicians.

5. The rapidly changing nature of the knowledge base, clinical applications, information technology and policy environment for genetics in primary care presented a challenge for all concerned in this project. It will likely prove helpful in dynamic areas like this if in the future federal funders would plan specific opportunities to interlink and coordinate related and/or complimentary grants and contracts. By this means the Federal government could make most efficient use of its investments by fully leveraging the accumulating breadth of knowledge and experience as well as the expanding network of scholars and resources related to this topic. GPC project examples of how these opportunities arise, and of the successes and challenges to efficient project coordination, include, of course, the Genetics Tools project, as well as the GeneTests Website, the CDC Family History Tools Project, and the SACGT Educational Summit, among others.

Recommendations to Primary care and Genetics Communities

1. A major accomplishment of GPC was the creation a group of academicians from primary care and genetics who have initiated and sustained (at least over the course of the GPC) a dialogue. Future programs drawing on this model of stimulating and sustaining a national dialogue are recommended.

2. The GPC was about marrying genetics with primary care. The GPC initiated a process of bringing primary care and genetics together in a meaningful way. Mechanisms for furthering this dialogue, building on the GPC model of bringing the two communities together to learn together and teach together, are strongly recommended. The work of the GPC workgroups elucidated critical issues at the forefront of the interface between genetics and primary care. Taking the draft products and concepts elucidated in these four areas (cultural competence, family history taking, red flags, evidence-based medicine) and defining a research agenda for the future around the most critical issues is recommended.

3. Five years after the GPC was launched, the purpose of the GPC, as articulated in the proposal to fund the contract, is as compelling as ever. As stated in the Technical Proposal (August 1998), *“Changes in the health care delivery system occurring nationwide bring to the forefront the role of the primary care physician to ensure appropriate care for patients while containing costs. With the rapid growth of knowledge of genetics, primary care physicians need new knowledge and skills to function in this role with regard to genetic diseases. Primary care faculty need to acquire knowledge and skills necessary to teach future physicians how to prevent, diagnose, and manage genetic diseases within the evolving context of the health care delivery system.”* The increasing importance of the work of the GPC and of genetics as primary care evolves toward the future cannot be understated. The importance of genetics factors in disease

is important to emphasize in situations where there is a huge evidence base as well as in areas where there is far less evidence. A balanced approach in consideration of the evidence base in genetics is important to maintain as primary care and genetics continue to evolve. Additionally, the ethical, legal, social and cultural implications are going to become increasingly important as more knowledge is gained with respect to the impact of genetics on disease and health outcomes. Continued work in these critical directions is recommended.

Assessment of Degree of Success Achieved

The GPC Project's goal was to enhance the ability of faculty to incorporate the clinical application of genetic information into undergraduate and graduate primary care medical education. This goal was successfully met through training of twenty faculty teams from across the country in development and implementation of faculty development around genetics into their primary care teaching programs.

The success of the GPC Project goes beyond the training of twenty faculty teams, however. The GPC Project also accomplished the attainment of an active, national dialogue between the primary care and genetics communities which will continue beyond project funding. The GPC produced tangible products, many of which are still undergoing revisions. The GPC Curriculum and the products of the four GPC workgroups stand out in this regard.

In sum, the success of the GPC has exceeded the contractual expectations outlined at its inception in 1998.

ATTACHMENT 1

Genetics in Primary Care (GPC): A Faculty Development Initiative Advisory Committee Organizations

PRIMARY CARE ORGANIZATIONS

Family Medicine

Society of Teachers of Family Medicine
American Academy of Family Physicians
Society of Teachers of Family Medicine Group on Predoctoral Education
Association of Departments of Family Medicine
Association of Family Practice Residency Directors
American Board of Family Practice

Internal Medicine

Society of General Internal Medicine
American College of Physicians
Clerkship Directors in Internal Medicine
Association of Professors of Medicine
Association of Program Directors in Internal Medicine
American Board of Internal Medicine

Pediatrics

Ambulatory Pediatric Association
American Academy of Pediatrics
Council on Medical Student Education in Pediatrics
Association of Medical School Pediatric Department Chairmen
Association of Pediatric Program Directors
American Board of Pediatrics

Other

Medicine-Pediatric Program Directors Association

OTHER SPECIALTY ORGANIZATIONS

American College of Obstetricians and Gynecologists
Association of Professors of Gynecology and Obstetrics
Association of Teachers of Preventive Medicine

OSTEOPATHIC ORGANIZATIONS

American Osteopathic Association
American Association of Colleges of Osteopathic Medicine
American College of Osteopathic Family Physicians

GENETICS ORGANIZATIONS

American College of Medical Genetics
American Society for Human Genetics
Alliance for Genetic Support Groups
Association of Professors of Human Genetics

OTHER ASSOCIATIONS

American Association of Health Plans
American Medical Association
American Medical Student Association
Asian and Pacific Islander American Health Forum
Association of American Medical Colleges
Association of Schools of Public Health
National Hispanic Medical Association
National Medical Association

LISAISONS TO THE GPC ADVISORY COMMITTEE

National Coalition for Health Professional Education in Genetics
National Institutes of Health
Centers for Disease Control and Prevention
Agency for Health Care Policy and Research

ATTACHMENT 2:

Genetics in Primary Care (GPC): A Faculty Development Initiative PROJECT MEMBERS 1998-2003

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