Original Article

Extending Comprehensive Cancer Center Expertise in Clinical Cancer Genetics and Genomics to Diverse Communities: The Power of Partnership

Deborah J. MacDonald, PhD, APNG; Kathleen R. Blazer MS, CGC, EdDc; and Jeffrey N. Weitzel, MD;
Duarte, California

Key Words
Cancer genetics, community, genetic counseling, genetic education, personalized medicine

Abstract
Rapidly evolving genetic and genomic technologies for genetic cancer risk assessment (GCRA) are revolutionizing the approach to targeted therapy and cancer screening and prevention, heralding the era of personalized medicine. Although many academic medical centers provide GCRA services, most people receive their medical care in the community setting. However, few community clinicians have the knowledge or time needed to adequately select, apply, and interpret genetic/genomic tests. This article describes alternative approaches to the delivery of GCRA services, profiling the City of Hope Cancer Screening & Prevention Program Network (CSPPN) academic and community-based health center partnership as a model for the delivery of the highest-quality evidence-based GCRA services while promoting research participation in the community setting. Growth of the CSPPN was enabled by information technology, with videoconferencing for telemedicine and Web conferencing for remote participation in interdisciplinary genetics tumor boards. Grant support facilitated the establishment of an underserved minority outreach clinic in the regional County hospital. Innovative clinician education, technology, and collaboration are powerful tools to extend GCRA expertise from a National Cancer Institute–designated Comprehensive Cancer Center, enabling diffusion of evidenced-base genetic/genomic information and best practice into the community setting. (*JNCCN* 2010;8:615–624)

From the Division of Clinical Cancer Genetics, City of Hope Comprehensive Cancer Center, Duarte, California.

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Correspondence: Jeffrey N. Weitzel, MD, City of Hope, 1500 East Duarte Road, DPS Building, Duarte, CA 91010.
E-mail: jweitzel@coh.org

Rapidly evolving genetic and genomic technologies for genetic cancer risk assessment (GCRA) are revolutionizing the approach to targeted therapy and cancer screening and prevention, heralding the era of personalized medicine. Although academic health centers have traditionally led the diffusion of new technologies into community practice, commercial availability and marketing of genetic testing have accelerated the uptake of testing in the community setting, where clinicians are often inadequately prepared to select, apply, and interpret genetic tests. Consequently, many questions remain about the composition of the personalized medicine workforce and challenges related to developing and sustaining best practices in GCRA in the community setting. This article describes some alternate approaches to delivery of high-quality GCRA services that leverage the expertise of the academic health center to promote access and quality care through advanced training and ongoing practice-centered support for community-based clinicians.

Cancer Genetics Overview: Trends and Gaps in State of Knowledge

Although only 5% to 10% of cancers are known to be associated with highly penetrant hereditary syndromes, thousands of cancer cases are attributable to hereditary predisposition, and the magnitude of risk conferred by these altered genes is dramatic.[1] More than 50 cancer-associated syndromes have a genetic basis, and several new cancer-associated genes are reported every year.[2] Genetic tools play an increasing role in risk assessment and testing interventions for a broad spectrum of common cancers.[3]

The GCRA process, which incorporates genetic analysis and empiric risk models to estimate cancer risk and provide personalized, risk-appropriate cancer screening and risk-reduction strategies for individuals and families, requires knowledge of genetics, oncology, and patient and family counseling skills, and involves more provider time than most other clinical services.[1,4]

Risk assessment for many highly penetrant cancer predisposition syndromes has clear clinical efficacy. GCRA increases adherence to surveillance, which is associated with diagnosis of earlier-stage tumors.[5] Numerous studies have shown the sensitivity of breast MRI in women who are *BRCA*-positive.[6] Retrospective studies of *BRCA* carriers indicate that adjuvant tamoxifen[7] and risk-reduction mastectomy can significantly reduce the risk for new primary breast cancer, up to 50% and 90%, respectively.[8] Risk reduction salpingo-oophorectomy provides 90% risk reduction for ovarian cancer and may substantially lower breast cancer risk in premenopausal women with a *BRCA* mutation.[9,10] Insights about the role of *BRCA* genes in DNA repair have led to the first targeted therapies for *BRCA*-associated cancers.[11] Similarly, strategies for evaluation of hereditary colon cancer risk continue to evolve.[12,13] Importantly, colonoscopic screening is effective in early detection and prevention of colon cancer in Lynch syndrome.[14]

As cancer genetics diagnostic and risk assessment tools move from bench to bedside, broad-spectrum clinical research will be in greater demand to further the understanding of how genetic technologies impact individuals, families, and society at large. Although a growing body of research is addressing questions about psychosocial outcomes and consequences of genetic testing for cancer risk, much more work is necessary to understand factors affecting quality of life and develop appropriate interventions and decision aides. Health services research is also needed to investigate the problems and limitations of delivering cancer genetics services to the larger community, including underserved populations.

Research on cost-effective mechanisms to transfer state-of-the-art cancer genetics technology into clinical practice are needed to enhance cancer prevention and control efforts in the community.[15] This challenge is particularly acute for the emerging field of genomics and personalized medicine.[16] Recent discoveries from genome-wide association studies (GWAS) of low-penetrance genetic variants with modest associated risk are changing the paradigm of how genetic information is delivered (Figure 1) and challenging clinicians to keep abreast of these advances.[17,18]

Commercial laboratories are capitalizing on GWAS by offering genome scans for single nucleotide polymorphisms associated with disease risk, and translating that risk into absolute risk estimates using various algorithms. However, little is known about whether these algorithms are well calibrated and the risk estimates provided by genome scans are accurate. A recent small study comparing 2 direct-to-consumer companies found differences in relative risk predictions for cancer, heart disease, diabetes, and other conditions for the same set of individuals, attributed partly to discrepancies in markers used to calculate relative risk and risk determination methods.[19] Furthermore, these genomic profiles are of uncertain clinical efficacy, because the reported risk is generally too small to form an appropriate basis for clinical decision-making.[20]

The recently revised ASCO Policy Statement on genetic and genomic testing highlights the difficulties in assigning clinical efficacy and the potential hazards of non-professionally mediated genetic analyses.[17]

Transition From the Multidisciplinary Academic Health Center Model to Community-Based GCRA

The earliest GCRA delivery models emerged from the academic health center setting, where GCRA is conducted through one or more consultative sessions with an interdisciplinary team that may include genetic counselors, advanced practice nurses, one or more physicians (generally a medical oncologist or geneticist), and, in some settings, a mental health

	Tests for Which Clinical Utility Is Accepted	Tests for Which Clinical Utility Is Uncertain
Professionally Mediated	Quadrant 1 e.g., MD ordered testing for high penetrance susceptibility (such as *BRCA1/2, MLH1/MSH2*)	Quadrant 1 e.g., MD ordered testing for low penetrance mutations (such as *CHEK2*)
Not Professionally Mediated	Quadrant 3 e.g., DTC testing for high penetrance susceptibility (such as *BRCA1/2, MLH1/MSH2*)	Quadrant 4 e.g., DTC testing for low penetrance variants of uncertain clinical utility (such as breast cancer risk SNPs)

Figure 1 Clinical utility of genetic and genomic testing.
When considering the future development of germline genetic testing in oncologic care, it is useful to think of tests with regard to their position along 2 axes. The first axis identifies whether or not the test has accepted clinical utility. The second axis describes whether the test was obtained through the mediation of a health care provider (HCP) with whom the individual being tested had an ongoing relationship, or through a direct-to-consumer (DTC) channel. To date, most genetic testing for cancer susceptibility can be categorized as professionally mediated and of accepted clinical utility (quadrant 1). As the fields of oncology and genetics continue to progress and become increasingly intertwined, HCPs will need to develop a working knowledge of tests that fall under the other 3 quadrants.
Abbreviations: MD, doctor; SNP, single nucleotide polymorphism.
From Robson ME, Storm CD, Weitzel J, et al. American Society of Clinical Oncology policy statement update: genetic and genomic testing for cancer susceptibility. J Clin Oncol 2010;28;895. Reprinted with permission. © 2010 American Society of Clinical Oncology. All rights reserved.

professional.[21] Although many academic health centers across the nation provide comprehensive GCRA services, most people receive medical care in the community setting. Unfortunately, few community-based medical centers are equipped to deliver this service model, because of a lack of adequately trained personnel and an unfavorable reimbursement climate for counseling-dominated care.[22–24]

Various practice models are evolving to meet the growing demand for GCRA services in the community setting (Table 1).[24–26] Some of these models combine efficient patient care with best practices in GCRA. Others may not adequately address important nuances inherent in the GCRA process that inform several aspects of patient care, including optimal testing strategies, appropriate interpretation of uninformative test results, consideration of alternate genetic etiologies, psychosocial and family communication dynamics, and other factors.

The City of Hope Model for Extending Cancer Genetics Expertise to the Community

The City of Hope Division of Clinical Cancer Genetics was established in 1996 to be a national leader in the advancement of cancer genetics, screening, and prevention, through innovative patient care, research, and education. The Division includes the Cancer Screening & Prevention Program Network (CSPPN) for full-spectrum GCRA services, and the Cancer Genetics Education Program (CGEP) developed to educate medical professionals about the emerging science and clinical efficacy of cancer genetics (Figure 2). The CSPPN and CGEP facilitate the integration of genetics services in the community and provide access to a robust program of laboratory and health services research through an institutional review board–approved Hereditary Cancer Registry prospective study protocol.[21,27]

Initiated in 1996, the Registry has accrued more than 6000 participants with 4 to 5 generation family histories and blood/DNA samples, with associated psychosocial and clinical follow-up data (e.g., screening and risk reduction behavior, risk communication). The consent document and process is explicit about sharing anonymized biospecimens with other investigators. The Registry has facilitated scholarly research created in collaboration with community partners in the realms of genetic epidemiology, biobehavioral health disparities, and health services research. Data from the Registry enable participation in the multi-institutional consortia necessary for assembling sufficient hereditary cases for epidemiolog-

Table 1 Models of Practice for Genetic Cancer Risk Assessment

Model	Benefits	Limitations
Academic/Medical Center Model		
Patients referred to cancer genetics program, seen by interdisciplinary team (GC, nurse, physician); pre- and post-genetic testing counseling and integrated risk assessment (COH comprehensive model)	• Comprehensive state-of-the-art personalized GCRA delivery, including genetics-focused physical examination and medical management • Level of care expected of a cancer center setting; billable patient visits • Critical research linkage	• Throughput may be limited by physician availability, personnel costs, and time intensity of providing comprehensive GCRA service • Possible community clinician barriers to referral
Community Models		
Community center partners with academic center of excellence	• Advanced practice-based support from the academic center for community center clinicians • Patients receive high-level care • Access to the academic center clinical and research data forms and genetics research	• Possible fees for academic oversight • Time commitment for quality assurance activities
Oncologist or other physician initiates genetic testing; only refers patients with positive or ambiguous results to genetics provider	• Immediate offering of genetic test may be effective means of GCRA delivery for carefully selected patients • Complicated cases referred to genetics provider for thorough counseling and risk assessment	• Nuances of GCRA underestimated; possible errant test/testing approach; patient and family may be falsely reassured • Patient may not be given sufficient information to make informed decision for genetic testing/testing strategies
Patient referred to cancer risk counselor (GC/APN) for genetic counseling/testing, summary note sent to referring physician	• Meaningful counseling and risk assessment service provided by qualified personnel	• Patient given general vs. tailored risk-reduction recommendations • No or limited billable GCRA service • No or limited physical examination to help guide assessment • Limited cancer genetics research participation
Triage model APN performs initial personal/family history screening; triages to GC for further assessment; referring physician provides patient-recommendations	• Streamlined referral process • Patients requiring individual counseling identified and seen in a timely manner • Efficient use of limited genetics provider resources	• APN/GC may not have adequate cancer genetics knowledge to triage/assess appropriately • Referring physician may not be familiar with current risk level–based medical management • Cancer genetics research participation limited
Group model At-risk individuals attend a group-focused cancer genetics presentation, followed by individual counseling sessions as indicated based on risk or as desired by patient	• Efficient for providing overview of GCRA and prescreening referred patients • Efficient use of limited genetics provider resources	• Ineffective for anxious patients, particularly if recent cancer diagnosis • Time constraints to address individual questions • Group session not a billable service • Patient confidentially/privacy may be compromised
Telemedicine Community center servicing a geographically or socioeconomically underserved population partnered with an academic center of excellence	• Patients gain access to academic center-level of clinical care, including opportunities for research participation • Efficient use of limited genetics provider resources	• Requires telemedicine setup and time commitment for quality assurance • Consultation services may not be billable • May require funding to establish partnership
Remote open access model Educational materials and phone or Internet counseling provided by for-profit company	• Counseling may be scheduled at the convenience of the patient (possibly from home) • Possible cost savings	• Limited quality outcomes data • Possible lack of local clinician communication or follow-up • No research opportunities

Abbreviations: APN, advanced practice nurse; COH, City of Hope; GC, genetic counselor; GRCA, genetic cancer risk assessment.

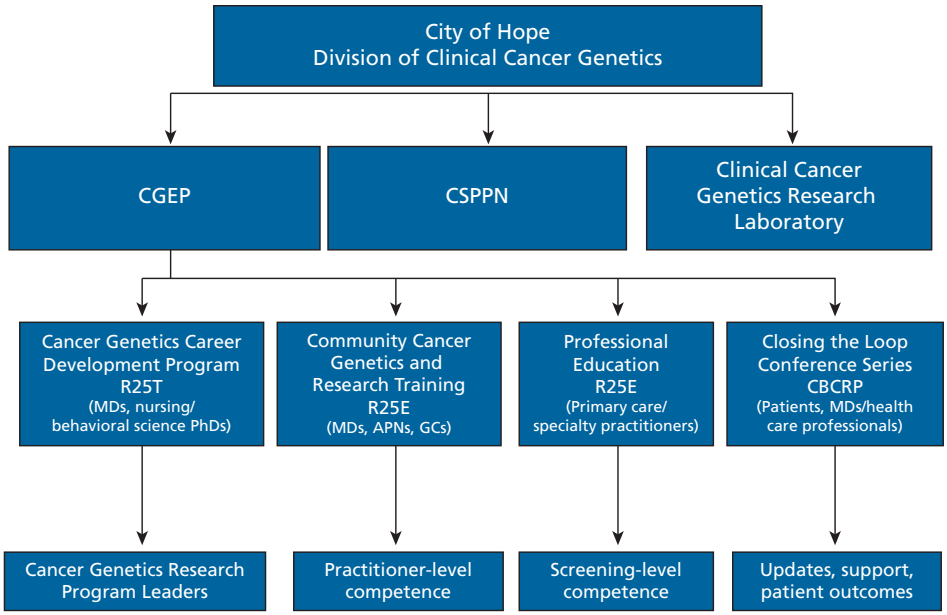

Figure 2 The program incorporates the clinical research resources of the City of Hope Department of Cancer Screening and Prevention Program and the multifaceted training expertise Cancer Genetics Education Program (CGEP), initiated in 1997 with guidance and expertise from the City of Hope Department of Nursing Education. The Cancer Genetics Career Development Program maximizes the resources and expertise of the CGEP for cancer genetics program leadership training. The program offers multi-institutional academic and research mentorship resources through collaborations with the City of Hope Beckman Research Institute and the Department of Preventive Medicine at University of Southern California. The community clinician education component is detailed in the text. Feedback from patients as stakeholders is accomplished through a series of conferences, with mixed methods of data collection. An advisory committee to the CGEP comprises key faculty in Nursing Research and Education, the Beckman Research Institute, and intra-and extramural professionals from the fields of education, law, bioethics, molecular genetics, and preventive medicine, and community-based advocates.
Abbreviations: APN, advanced practice nurse; CBCRP, Regents of the University of California Breast Cancer Research Program; CSPPN, Cancer Screening & Prevention Program Network; GC, genetic counselor.

ic study.[28] Furthermore, locally relevant and practical health services research enabled by the registry has influenced clinical practice guidelines.[29,30]

CSPPN

As a major component of NCI-Comprehensive Cancer Center status, the CSPPN serves as a resource to community medical centers and clinicians who generally would not have the infrastructure and expertise necessary to develop this model of care. A detailed description of the establishment of the CSPPN and City of Hope's hub-and-spoke community outreach program were described previously.[21] In brief, community-based centers are contracted with the City of Hope for program development, training in GCRA for personnel, and continuing practice-centered support to promote quality care. The program development activities are tailored to address the needs and resources of each community center. A site assessment may also be conducted by the City of Hope team to identify appropriate physical space for the GCRA sessions, preferably within or adjacent to the community center's medical or surgical oncology services. In addition to a thorough orientation to the City of Hope GCRA protocols, advice and assistance is provided regarding clinic and family history instruments and selection of pedigree database software.

Different Models for Different Settings

The CSPPN has provided comprehensive GCRA services to more than 6000 individuals and their families, with approximately 20% of these stemming from the satellite clinics. In the Cancer Center of Santa Barbara and St. Jude Medical Center, Virginia Crossen Cancer Center affiliates, an advanced practice nurse (APN) credentialed in genetics initiates risk assessment and enrollment in our Hereditary Cancer Reg-

istry. Patients are then seen by a CSPPN physician and the APN at a subsequent visit; the physician uses evaluation and management codes to bill for visits.

At Good Samaritan Medical Center in Arizona, an APN with board certification in genetic counseling provides cancer risk counseling and administers the program with clerical support, oversight by a local oncologist, and case-based guidance from the Clinical Cancer Genetics (CCG) Working Group (described later). Another genetic counselor was recently brought onboard to help with increasing referrals. Both counselors see patients independently and generate a patient visit note to the referring physician.

Similarly, with CSPPN support services, St. Joseph's Medical Center in Orange County, California hired a board-certified genetic counselor who completed an advanced 1-year trainee-ship in cancer genetics at the City of Hope to lead their GCRA program. With institutional and multidisciplinary support for the program from a medical oncologist, surgical oncologist, and colorectal surgeon, 2 additional genetic counselors have been hired to handle the increasing referral base. Development of the GCRA program, and accrual to the registry and related research, contributed to successful competition for an NCI community cancer center planning grant.

Additional CSPPN affiliated programs have been developed for underserved and minority communities. The best example is a project to deliver culturally competent GCRA at the Los Angeles County Olive View Medical Center, which serves a predominantly Hispanic community in Southern California. A key element of the program's success is genetic counseling provided by bilingual cancer risk counselors trained in culturally sensitive approaches to GCRA.[31] A critical component deemed necessary before program implementation was a commitment from the referring institution to provide risk-appropriate cancer screening and prevention for referred patients and an onsite bilingual patient coordinator to facilitate the process. The project success yielded a grant (Susan G. Komen Breast Cancer Foundation Grant # POP0600464) to examine an emerging social–cognitive theoretical model regarding perceived access to care and post-GCRA behaviors in this population.[32]

In addition, a recently established tele-health initiative (videoconference-mediated GCRA) between City of Hope and Toiyabe Indian Health Project (Indian Health Service) in Bishop, California is another example of meeting community need (the nearest genetic counseling program is at least a 4-hour drive) while addressing disparities and enhancing related health services research. Alternative modes of GCRA delivery may enable cost-effective community medical center participation. The choice of models depends partly on the availability of qualified staff and the local institutional economic environment. Billing for mid-level services is sometimes possible through facility fee or individual provider codes. Apprising administrators of potential downstream revenue from cancer screening, chemoprevention, and surgical risk-reduction interventions may help them justify underreimbursed program costs.[33–35]

Quality Assurance in GCRA: CCG Working Group and Topics in Cancer Genetics Research

CSPPN affiliates have ongoing access to the evidence-based updates and practice-centered support essential to sustaining an informed community-based GCRA practice through participation in 2 CME-accredited Web conference activities: CCG *Working Group* and *Topics in Clinical Cancer Genetic Research*. CCG Working Group (Figure 3) is an interdisciplinary cancer genetics case conference series conducted each week by the City of Hope clinical team. CSPPN and affiliated clinicians across the United States present cases from their community practices through Microsoft Live Meeting Web conference interface for discussion and recommendations on risk assessment, surveillance, risk management, and identification of research eligibility for cases covering the full spectrum of hereditary cancer. Table 2 provides a summary sampling of recommendations for community-based cases generated during CCG Working Group over a 17-week period.

Topics in Clinical Cancer Genetics is a weekly 1-hour Web seminar series focused on timely issues in clinical cancer genetics, cancer epidemiology, and cancer genetics research, alternating among didactic lectures, case-based literature reviews, and a basic research journal club. City of Hope faculty, guest lecturers from other academic institutions, CSPPN affiliates, and alumni of the City of Hope Intensive Course in Clinical Cancer Genetics (described lat-

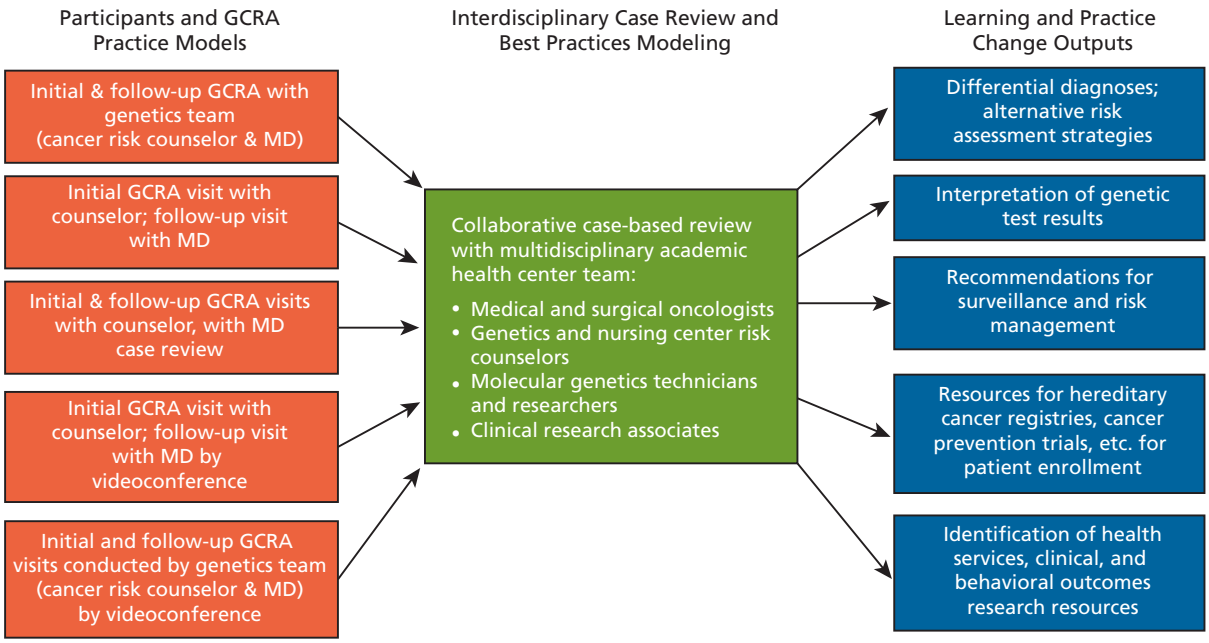

Figure 3 Clinical Cancer Genetics Working Group.
A weekly CME-accredited interdisciplinary cancer genetics case review conference. Participants learn the complex process of multidisciplinary cancer genetics case work and receive hands-on experience in cancer genetics case presentation, risk assessment, and management. Clinical experience gained from the City of Hope Cancer Screening & Prevention Program Network, coupled with multidisciplinary case discussion during the Clinical Cancer Genetics Working Group, form the cornerstone of community practice. Cancer center physicians and medical oncology faculty, fellows, molecular diagnostic laboratory faculty, and visiting community physicians attend in person or through Web conferencing.
Abbreviations: GCRA, genetic cancer risk assessment; MD, doctor.

er) are included in the roster of presenters to ensure that the topics covered address the practice-centered learning needs of the community-based participants.

Expanding the Expertise and Support of the Academic Health Center: The Intensive Course in Community Cancer Genetics and Research Training

Interdisciplinary GCRA training and CME activities are essential to extend the expertise and resources of the academic health center to the community-based setting. Oncology, genetics, nursing, and government health organizations (including ASCO, National Institutes of Health, American Society of Human Genetics, National Society of Genetic Counselors, Oncology Nursing Society, and International Society of Nurses in Genetics) and academic institutions offer cancer genetics seminars, workshops, and Web-based resources. The ASCO Task Force on Cancer Genetics Education produced a curriculum for oncologists and other health care providers entitled *Cancer Genetics & Cancer Predisposition Testing*, originally published in 1998 and updated in 2004.[36,37]

In response to the national need for specialized training in cancer risk assessment, the City of Hope conducts an NCI-funded (R25 CA112486) Intensive Course in Community Cancer Genetics and Research Training for community-based genetics and oncology practitioners.[38] The goal of the course is to increase the number of clinicians across the nation with practitioner-level competence in GCRA through a combined program of CME-accredited distance-learning didactics, face-to-face training, and post-course professional development activities.

Several CSPPN affiliate clinicians established their formal collaborations with the City of Hope as a consequence of their participation in the course. As depicted in Figure 4, 140 clinicians representing community-based clinical practices in 41 states and Canada, Brazil, Chile, and Spain completed the course as of December 2009. Upon completion of training, all course participants are invited to join the roster of CSPPN affiliates and intensive course alumni who participate in *Topics in Clinical Cancer Genetic Research* and CCG *Working Group* for ongo-

Table 2 A Snapshot of Multidisciplinary Quality Control*

Nature of Working Group Advice	Frequency of Advice
Change in diagnostic strategies	7
Identify testing candidates	42
Interpret test results	26
Provide risk assessment	42
Recommend management and follow-up	50
Confirm testing strategy	49
Determine if appropriate for rearrangement test	8
Expand differential diagnoses	27
Recognize secondary genetic pattern in family	11
Interpret pathology report	17
Consensus regarding phenotype	11
Interpret VUS results	6
Calculate mutation probability	7
Suggestions for research protocol eligibility	16
Other†	22
Cases advised over 17 weeks	248

*Recommendations for cases presented by community-based clinicians generated during Clinical Cancer Genetics Working Group web conferences.
†Other categories include family communication solutions, empiric risk management advice, requesting pathology report, insurance issues, and counseling strategies.
Abbreviation: VUS, variant of uncertain significance.

ing professional development and case-based support on return to their practice settings.

Technical Support for the CSPPN

The distance-mediated networking that sustains the CSPPN is enabled by information technology, with videoconferencing for telemedicine and Web conferencing for remote participation in the CCG Working Group, Topics in Cancer Genetics Research, and the distance-mediated learning and professional development activities of the intensive course. The Enterprise (multiclient server) version of Progeny (Progeny Software LLC, South Bend, Indiana) pedigree-drawing software was obtained and customized to the clinical and research needs of CSPPN. Each satellite purchased their own pedigree software license, and the City of Hope database framework with customized fields was distributed to each satellite program. Sending out updated versions of the database framework is critical to seamless compatibility, both for pedigree presentation at the working group and in sharing research data. In addition to technical support from the software company, 2 super users at the cancer center provide assistance with clinical research issues related to the database and interactions with the cancer center master database. Scannable forms were developed for clinic and family history questionnaires for use in the CSPPN, including forms for efficient data entry for the registry study.

Conclusions

Once delivered primarily through academic health centers, several alternative delivery models have evolved to extend GCRA services beyond the confines of the academic health care delivery system to the broader community.[17,21,24–27] Provision of GCRA is an important growing service for community-based clinicians. Limited health services and psychosocial research has addressed the underserved, underinsured, and many ethnic minorities, partly because of very limited access to GCRA services. Measures to increase access and cost-effectiveness are particularly important given limited available resources to address disparities.[3] Recent outcomes from the authors' research program indicate that providing GCRA to underserved Latinas at the Los Angeles County Olive View Medical Center is accepted in the community and prompts increased risk-appropriate follow-up care, despite relatively low acculturation.[32,39]

The rapid evolution of genetic information and direct-to-consumer and to-physician marketing by commercial genetic testing vendors are prompting a steady increase in the number and spectrum of clinicians who provide GCRA services in the community setting.[22,23,40] Despite the push toward nonprofessionally mediated genetic and genomic testing, ASCO and other leading oncology and genetics professional organizations continue to recommend that pre- and posttest counseling be conducted by clinicians with the necessary skills and experience.[17,30,41–43]

This article describes the benefits and limitations of several delivery models, focusing on the important role comprehensive cancer centers can take to promote and support high-quality GCRA in their com-

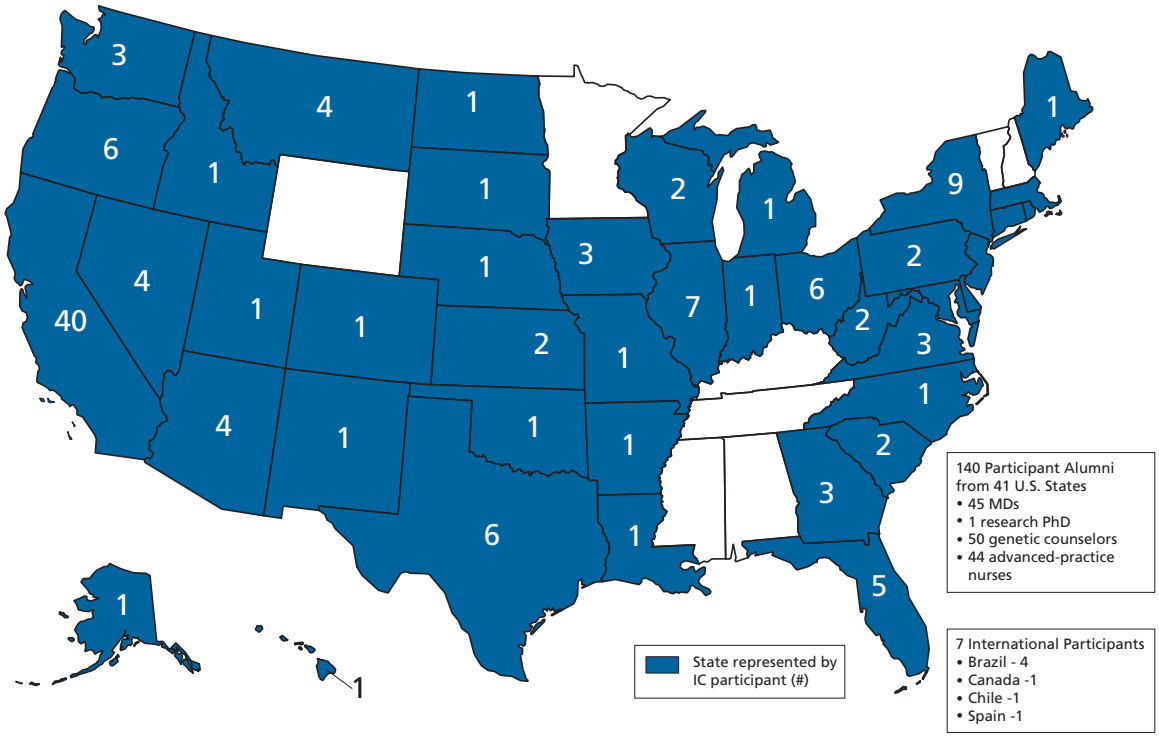

Figure 4 Distribution and composition of clinician alumni from the City of Hope intensive course in Clinical Cancer Genetics and Research. © Map Resources

munities. Regardless of the model used to address the demand for more efficient and broader coverage of GCRA services, no model should compromise informed decision-making. Considering the overwhelming interest in City of Hope cancer genetics education programs from busy clinicians from across the United States, quality is still important. A growing number of course alumni continue to participate in the CCG Community of Practice. As the legislative effort to reform health care proceeds, provisions must address current problems related to inadequate coverage for preventive care based on the evidence of cost-effectiveness and benefits of GCRA from the societal perspective.

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