
Genetic Services Policy Project Final Report

Appendix A: Dissemination Activities

Dissemination of results has been a major component of the **Genetic Services Policy Project**. The dissemination activities have taken many forms, from peer-reviewed publications and workshops to informal articles and presentations. The GSPP has attained a high rate of acceptance for peer-reviewed submissions—85 percent, or 34 out of 40. Project personnel have also taken part in 15 informal presentations and six written dissemination activities. Finally, we have held four in-person meetings of the national advisory committee, produced quarterly newsletter updates, and provided website resources. A summary count follows; see Appendix A.1 (page 3) for a full list.

Genetic Services Policy Project Dissemination Activities

- 8 published articles (peer-reviewed)
- 3 published articles (not peer-reviewed)
- 12 poster presentations (peer-reviewed)
- 14 formal presentations, including 7 workshops
- 15 informal presentations
- 6 informal written dissemination activities
- 6 peer-reviewed submissions that were not accepted
- 13 formal communications with advisory committee, including 4 annual face-to-face meetings

GSPP has produced eight peer-reviewed publications in the following journals: *American Journal of Managed Care*, *American Journal of Public Health*, *Genetics in Medicine*, *Health Affairs*, *Journal of Health Politics, Policy and Law*, and *Maternal and Child Health Journal*. Articles include topics such as economic analyses and evidence-based assessments of genetic services, genetics policy, utilization trends of genetics clinics, and genetic counseling for children with special health care needs. The 12 peer-reviewed posters address similar subjects. A list of article titles and authors is included in Appendix A.1.

GSPP has given a number of formal presentations. The conference organizers include American College of Medical Genetics, American Public Health Association, Centers for Disease Control and Prevention, Genetic Alliance, National Institutes of Health, and World Research Group. Dates and titles of presentations are included in Appendix A.1.

With the assistance of many members of our Advisory Committee, we developed a series of workshops that were delivered at meetings and conferences of some of the key trade associations represented by our advisors: AdvaMed, America's Health Insurance Plans, American Hospital Association, American Medical Association, Association of Genetic Technologists, Biotechnology Industry Organization, and Child Health Corporation of America. Between November 2006 and October 2007, we delivered seven workshops. The workshops allowed us to directly disseminate our work to hundreds of providers, managers and executives

in the health care delivery system. The response to our material was excellent, and those who attended felt that this was a very efficient method of dissemination. For those workshops that conducted evaluations, GSPP's presentations received consistently positive feedback. The presentation and evaluation materials from each workshop appear in Appendix A.2 (page 9).

Project personnel have also participated in a number of informal presentations to audiences such as the Western States Genetic Services Collaborative, the National Coordinating Center for the Regional Genetics and Newborn Screening Collaborative Groups, Washington State Genetics Providers Group, Washington State Perinatal Advisory Committee, the Institute of Medicine Cancer Policy Forum, and units within the University of Washington, the National Human Genome Research Institute, and the National Society of Genetic Counselors.

GSPP has taken advantage of informal opportunities to disseminate written materials to the National Conference of State Legislatures, the National Newborn Screening and Genetics Resource Center, and several chief medical officers. We sent a letter to the Secretary's Advisory Committee on Genetics, Health and Society, responding during the public comment period to the draft report, "Policy Issues Associated with Undertaking a Large U.S. Population Cohort Project on Genes, Environment, and Disease." We also had an informational display table at the National Society of Genetic Counselors' Annual Education Meeting. In addition, our website showcases GSPP's project updates and resources.

In sum, our dissemination activities have reached a broad audience on a range of topics related to genetic services. Our materials have been well received, as evidenced by our high publication success rate and the uniformly positive evaluation of our presentations.

Appendix A.1: Complete List of Dissemination Activities

Papers and Articles (peer-reviewed)

Date	Activity	Topic	Venue	Primary Person
October 2005	Article	Economic analyses of human genetics services: a systematic review	<i>Genetics in Medicine</i> . 2005 Oct;7(8):519-523.	Josh Carlson
October 2005	Article	The Case of BiDiI: A Policy Commentary on Race and Genetics	<i>Health Affairs</i> , web exclusive, October 11, 2005	Rick Carlson
April 2006	Article	Toward Evidence-based Assessment for Coverage and Reimbursement of Laboratory-based Diagnostic and Genetic Tests	<i>Am J Manag Care</i> . 2006;12:197-202	Rick Carlson, David Veenstra
February 2007	Article	Genetic Counseling, Insurance Status, and Elements of Medical Home: Analysis of the National Survey of Children with Special Health Care Needs	<i>Maternal and Child Health Journal</i>	Grace Wang
April 2007	Article	The role of genetics in the provision of essential public health services	<i>American Journal of Public Health</i> 97(4):620	Grace Wang
October 2007	Article	Utilization trends of genetics clinics excluding prenatal services in Washington State, 1995 to 2004	<i>Genetics in Medicine</i> . 9(10):713-718.	Grace Wang, Cindy Watts
October 2007	Article	Pharmacogenomic testing to prevent aminoglycoside-induced hearing loss in cystic fibrosis patients: potential impact on clinical, patient, and economic outcomes	<i>Genetics in Medicine</i> . 9(10):695-704.	Dave Veenstra
February 2008	Article	Preemptive Public Policy for Genomics	<i>Journal of Health Politics, Policy and Law</i> 33: 39-51	Rick Carlson

Papers and Articles (not peer-reviewed)

Date	Activity	Topic	Venue	Primary Person
July 2004	Article	Describing GSPP	National Society of Genetic Counselors' newsletter <i>Perspectives</i>	Deb Lochner Doyle Amber Roche
May 2005	Article	Describing GSPP	Association of Maternal and Child Health Programs newsletter <i>Pulse</i>	GSPP personnel
June 2006	Article	Third Party Payer Perspectives	Health Industry Forum Foundation	Rick Carlson

Posters (peer-reviewed)

Date	Activity	Topic	Venue	Primary Person
May 2005	Poster presentation	A Systematic Review of Economic Evaluations of Genetic Testing Technologies	International Society for Pharmacoeconomics and Outcomes Research in Washington, D.C.	Scott Ramsey
July 2005	Poster presentation	A Systematic Review of Economic Evaluations of Genetic Testing Technologies	International Health Economics Association in Barcelona, Spain	Scott Ramsey
October 2005	Poster presentation	Organization, Administration and Funding of State Genetic Services Programs	American Society of Human Genetics Annual Meeting in Salt Lake City, UT	Grace Wang
March 2006	Poster presentation	Pharmacogenomics and aminoglycoside-induced hearing loss in cystic fibrosis patients	American College of Medical Genetics Annual Clinical Genetics Meeting in San Diego, CA	Julie Harris
September 2006	Poster presentation	Utilizations of Genetics Clinics in Washington, 1995 – 2004	University of Washington Annual Gathering of Health Sciences Schools incoming students	Grace Wang
November 2006	Poster presentation	Factors associated with need and use of genetic counseling: An analysis of the National Survey of Children with Special Health Care Needs	American Public Health Association Annual Meeting in Boston, MA	Grace Wang
November 2006	Poster presentation	Policy implications of cost effectiveness analysis for genetic testing: A case study	American Public Health Association Annual Meeting in Boston, MA	Julie Harris
November 2006	Poster presentation	Integrating Personalized Medicine into the Health Care System: A Comprehensive Study of Stakeholder Groups	American Medical Association meeting	Patricia Deverka (GSPP Advisor)
November 2006	Poster presentation	Through the media lens: Analyzing the news messages Americans receive about genetics	National Society of Genetic Counselors' Annual Education Conference in Nashville, TN	Amber Roche
November 2006	Poster presentation	Integrating genomics into the healthcare system: opportunities for collaborations by stakeholders	National Society of Genetic Counselors' Annual Education Conference in Nashville, TN	Grace Wang Amber Roche
November 2006	Poster presentation	Proving Genomics: A Workshop for Physicians	Accepted – Society of Teachers of Family Medicine Annual Spring Conference in April in Chicago	Rick Carlson
March 2007	Poster presentation	Utilization Trends of Genetics Clinics in Washington State, 1995 to 2004	American College of Medical Genetics annual meeting in Nashville, TN, in March 2007	Grace Wang

Formal Presentations and Workshops

Date	Activity	Topic	Venue	Primary Person
September 2005	3 Panel presentations	Payment and reimbursement	Access to Quality Testing for Rare Disorders: National Institutes of Health (NIH) National Conference in Rockville, MD	Rick Carlson
March 2006	Presentation	Evaluation of Genomic Applications in Practice and Prevention (EGAPP) assessment of genetic testing; program review and follow-up	Centers for Disease Control and Prevention in Atlanta, GA	Rick Carlson
March 2006	Presentation	Stakeholders' Perspectives on the Delivery of Genetic Services	American College of Medical Genetics Annual Clinical Genetics Meeting in San Diego, CA	Rick Carlson, Deb Lochner Doyle
July 2006	Presentation	Personalized Medicine Landscape: challenges and opportunities for consumers	Genetic Alliance Annual Conference in Bethesda, MD	Rick Carlson
October 2006	Presentation	Quality, Access, and Sustainability of Biochemical Genetic Testing	Joint National Institutes of Health (NIH) Office of Rare Diseases – Centers for Disease Control and Prevention in Atlanta, GA	Rick Carlson, Michele Puryear
November 2006	Presentation	A model for determining the budget impact of expanded newborn screening	American Public Health Association Annual Meeting in Boston, MA	Wylie Burke
November 2006	Presentation	Genomics Stakeholder Workshop	American Medical Association meeting	Rick Carlson, David Veenstra
November 2006	Presentation	Genomics Stakeholder Workshop	AdvaMed meeting – Molecular Diagnostics: Development, Regulation, & Reimbursement	Rick Carlson, Jeff Bauer (GSPP advisor)
April 2007	Presentation	Transforming Health Care: The emergence of Genetic Services in Medicine and Health Care	Child Health Corporation of America	Rick Carlson
May 2007	Presentation	Proving Genomics: What Do Payers and Providers Need?	BIO (Biotechnology Industry Organization) International Convention, Boston, MA	Rick Carlson, Jeff Bauer (advisor)
June 2007	Presentation	Proving Genomics	Association of Genetic Technologists' Annual Meeting, Denver, CO	Rick Carlson, Deb Lochner Doyle
June 2007	Presentation	Proving Genomics: A Workshop for Payers	America's Health Insurance Plans Annual Meeting in Las Vegas, NV	Rick Carlson
July 2007	Presentation	Integrating Genomics: What Do Hospitals Need?	American Hospital Association / Health Forum's Leadership Summit in San Diego, CA	Cindy Watts
November 2007	Presentation	Integrating Medical Genetics and Genetic Testing to Enhance the Value of Healthcare Delivery and Disease Prevention	Genetic Testing & Genetic Risk Assessment for Health Plans, World Research Group	Rick Carlson

Informal Presentations and Workshops

Date	Activity	Topic	Venue	Primary Person
May 2005	Presentation	Year 3 proposal narrative as background for a task force	National Society of Genetic Counselors' Genetic Services Delivery Task Force	Daragh Conrad (GSPP Advisor)
September 2005	Web cast presentation	Financing of Genetic Services based on GSPP State Genetics Profiles data	National Coordinating Center for the Regional Genetics and Newborn Screening Collaborative Groups	Deb Lochner Doyle
September 2005	Conference participation	Genetics and newborn screening services	National Coordinating Center for Regional Genetics and Newborn Screening Collaborative Groups in Washington, D.C.	Grace Wang
September 2005	Presentation	Project update	Western States Regional Genetics Collaborative meeting in Las Vegas, NV	Amber Roche
December 2005	Discussion / presentation	Integrating genetic services into current system	Joint Centers for Disease Control and Prevention-Group Health Cooperative meeting in Seattle, WA	Rick Carlson
February 2006	Presentation	Assessed databases, described GSPP activities	GeneTests in Seattle, WA	Rick Carlson
March 2006	Presentation	GSPP state genetics profiles, case studies, and cross-cutting policy format	Washington State Genetics Provider Group in Kent, WA	Deb Lochner Doyle
June 2006	Presentation	Project update	HRSA offices in Washington, D.C.	Rick Carlson
June 2006	Discussion	Reimbursement policy	National Human Genome Research Institute	Rick Carlson
June 2006	Utility, infrastructure	Developing guidance process for evidence-based coverage decisions regarding genetic services	Diagnostic developers and payers	Rick Carlson
June 2006	Briefing attendance	A Bill to improve and expand the use of molecular genetic tests and therapeutics	Senator Barack Obama's staff in Washington, D.C.	Rick Carlson
October 2006	Presentation	Update on the work of the Genetic Services Policy Project	Western States Genetic Services Regional Collaborative Summit	Amber Roche
October 2006	Presentation	Preemptive Public Policy for Genomics	UW Dept of Health Services Policy Seminar Series	Rick Carlson
February 2007	Presentation	Genetic Services Policy Project findings	Washington State Perinatal Advisory Committee	Deb Lochner Doyle
March 2007	Presentation	Billing and reimbursement issues for genetic services	Institute of Medicine Cancer Policy Forum	Deb Lochner Doyle

Informal Written Dissemination

Date	Activity	Topic	Venue	Primary Person
August 2005	Fact sheets	GSPP overview	National Conference of State Legislatures Annual Meeting in Seattle, WA	Candi Wines
September 2005	Fact sheets	Genetic Services Policy Project overview	Requested by and sent to 7 advisors and chief medical officers	Candi Wines
September 2005	Template – state genetics profiles	State genetics profiles and GSPP overview	Sent to National Newborn Screening and Genetics Resource Center	Candi Wines
October 2005	Flow chart diagrams	Organization, Administration and Funding of State Genetic Services Programs	Sent to National Conference of State Legislatures for a booklet they are creating	Grace Wang
July 2006	Public Draft Comment Letter	Comments on public draft of SACGHS' report: Policy Issues Associated with Undertaking a Large U.S. Population Cohort Project on Genes, Environment, and Disease	Secretary's Advisory Committee on Genetics, Health, and Society	GSPP personnel
November 2006	Display table	GSPP State Genetic Profiles, Fact Sheets, Informational Tear-away Sheets	National Society of Genetic Counselors' Annual Education Conference in Nashville, TN	Amber Roche

Submissions That Were Not Accepted

Date	Activity	Topic	Venue	Primary Person
June 2005	Panel presentation	Impact of genetic services on disparities in vulnerable populations	Submitted to Grantmakers in Health	Rick Carlson
October 2005	Panel presentation	The role of genetic services in health care: barriers and opportunities	Submitted to American Society of Human Genetics Annual Meeting	Deb Lochner Doyle
October 2005	Article	Expenditures for Genetic Services in the United States: An Overview	Submitted to <i>Health Affairs</i>	Grace Wang
January 2006	Article	Stakeholders' perspectives regarding genetics and genetic services in the United States	Submitted to <i>Clinical Genetics</i>	Grace Wang
January 2006	Panel presentation	Policy Research on Genetic Services: New Science Meets Old Paradigm	Submitted to Academy Health Annual Research Meeting	Carolyn Watts, Deb Lochner Doyle
April 2006	Poster	Promoting Health by Integrating Genomics into the Healthcare System: Opportunities for Collaborations by Stakeholders	Centers for Disease Control and Prevention annual National Health Promotion Conference	Grace Wang
Continuous	Website	GSPP updates and resources	GSPP's website	GSPP personnel

Dissemination to the Advisory Committee

Date	Activity	Topic	Venue	Primary Person
September 2004	Presentations / Conference	Update to Advisory Committee on GSPP Year 1	Annual Advisory Committee Meeting, Washington D.C.	Project personnel
April 2005	Presentations / Conference	Update to Advisory Committee on GSPP Year 1	Annual Advisory Committee Meeting, Chicago, IL	Project personnel
June 2005	GSPP update	Annual summary sent to advisors	Via email	GSPP personnel
September 2005	GSPP update	Quarterly communication with advisors	Via email	GSPP personnel
November 2005	GSPP update	Quarterly communication with advisors	Via email	GSPP personnel
April 2006	Presentations / Conference	Update to Advisory Committee on GSPP Year 2	Annual Advisory Committee Meeting, Washington D.C.	Project personnel
June 2006	GSPP update	Annual summary sent to advisors	Via email	GSPP personnel
August 2006	GSPP update	Quarterly communication with advisors	Via email	GSPP personnel
February 2007	GSPP update	Quarterly communication with advisors	Via email	GSPP personnel
April 2007	GSPP update and review	Quarterly communication with advisors	Via email	GSPP personnel
May 2007	Presentations / Conference	Update to Advisory Committee on GSPP Year 3	Annual Advisory Committee Meeting, Washington D.C.	GSPP Personnel
August 2007	Backgrounder distribution	Backgrounder on Pharmacogenomics for the Pharmaceutical and Biotechnology Industries: Basic Science, Future Scenarios, Policy Directions	Mailed a copy of backgrounder to each GSPP advisor	Rick Carlson
October 2007	GSPP update	Quarterly communication with advisors	Via email	GSPP personnel

Appendix A.2: Summary of Evaluations from Genomics Workshops

Organization	Conference Title	Location, Date	Workshop Title	Presenters
American Medical Association	2006 Interim Meeting of the AMA House of Delegates	Las Vegas, NV November 12, 2006	Proving Genomics: A Workshop for Physicians	Rick J. Carlson, JD, Genetic Services Policy Project David Veenstra, Pharm D., PhD, Genetic Services Policy Project
AdvaMed	Molecular Diagnostics: Development, Regulation, and Reimbursement	Washington, DC November 16, 2006	Proving Genomics: A Stakeholder Workshop	Rick J. Carlson, JD, Genetic Services Policy Project Jeffrey C. Bauer, PhD, Senior Vice President, ACS Healthcare Solutions Paul Campbell, Managing Director, EBG Advisors
Child Health Corporation of America	Strategic Planning and Business Development Forum	Los Angeles, CA April 26, 2007	Transforming Health Care: The emergence of Genetic Services in Medicine and Health Care	Rick J. Carlson, JD, Genetic Services Policy Project
Biotechnology Industry Organization	BIO International Convention – New Ideas: Bold Ventures, Global Benefits	Boston, MA May 6-9, 2007	Proving Genomics: What do Payers and Providers Need?	Rick J. Carlson, JD, Genetic Services Policy Project Jeffrey C. Bauer, PhD, Senior VP, ACS Healthcare Solutions Paul M. Campbell, MS, Managing Director, EBG Advisors
Association of Genetic Technologists	32 nd Annual Meeting	Denver, CO May 31-June 3, 2007	Integrating Genetic Services into Mainstream Health Care	Rick J. Carlson, JD, Genetic Services Policy Project Debra Lochner Doyle, MS, CGC, Genetic Services Policy Project
America's Health Insurance Plans	Annual Meeting	Las Vegas, NV June 20-22, 2007	Proving Genomics: A Workshop for Payers	Rick J. Carlson, JD, Genetic Services Policy Project Allan J. Ebbin, MD, MPH, Vice President, Healthcare Quality and Education, Sierra Health Services
American Hospital Association	2007 AHA/Health Forum Leadership Summit	San Diego, CA July 22-24, 2007	Integrating Genomics: What Do Hospitals Need?	Carolyn Watts, PhD, Genetic Services Policy Project Marc Williams, MD, Director, Clinical Genetics Institute, Intermountain Healthcare

American Medical Association Evaluation

Audience: 70 senior level physicians

Evaluation: The AMA used its own evaluation form following the presentation.

	Strongly Agree			Strongly Disagree	
	1	2	3	4	5
The program was well organized.	31	23	3	2	1
The learning objectives were adequately addressed.	25	26	4	4	0
I can now discuss the evolving technology of genomics.	12	31	14	3	0
I can now describe the current scope of genetic testing services.	13	31	13	3	0
I can now discuss the findings and policy recommendations of the Genetic Services Policy Project.	8	25	18	5	2
I can now describe the clinical utility of personalized medicine.	13	32	13	2	0
I can now identify the uses of genetic data for predictive testing.	10	31	14	5	0
I can now describe the fundamentals of pharmacogenomics.	15	30	12	3	0
	Yes			No	
Did you perceive any commercial bias in the presentation?	1 (No explanation given)			54	

Comments/Suggestions:

Several “outstandings.” “Excellent, exciting program.” “More of the same.” “Update annually.” “Excellent presentations by Rick Carlson and David Veenstra.” “Very Good, thanks!” “Very interesting – Good to get real scoop on what is/isn’t out there and how rapidly (or not) this is likely to unfold.” “No current impact.” “Great speakers, excellent information, well done!” “Tough topic, very complex.” “Great discussion.” “Liked combination of speakers and having socio-economic context for the technical information.” “Good overview – not much news.” “I have a real interest in slow metabolizers and that was very helpful.” “Wish more physicians attended and participated. This is an important field. Thanks for the good handouts.”

“Expand discussion of prediction testing. How can technology help people alter their lifestyle?” “Less quotations and predictions, more about present facts and uses.” “More details.” “Mention proteomics.” “Provide list of references.” “Explore more generalized genetic testing (mitochondrial DNA) in exploring racial/genetic background of individuals. “Time lapse prediction” “Longer, more depth” “Information that is currently not available, more specifics re: testing and uses.”

TOTAL OF 64 CME forms returned.

AdvaMed Evaluation

Audience: The audience numbered about 200, and was comprised of senior managers, mostly marketing, product and business development from various diagnostic companies.

Evaluation: AdvaMed did not conduct presentation evaluations.

Child Health Corporation of America Evaluation

Audience: 30 strategic planning and business development employees

Evaluation: CHCA collected written comments and feedback from attendees:

- Engaging - intriguing - thought provoking – GREAT
- Thank You Thank You Thank You - Brilliant, Helpful, Fabulous
- Very enlightening, Excellent, liked his approach. We need to keep this item on our agenda for future meetings.
- Would have liked more time.
- Very interesting!
- Unclear how message can be taken back for some sort of implementation.
- Wonderful view of the future.
- Awesome - though provoking.
- I'd love to hear more on this - maybe do some roundtables on it?
- This was a very informative and thought provoking lecture.

Biotechnology Industry Organization Evaluation

Audience: There were approximately 300 biotechnology executives in attendance.

Evaluation: BIO did not conduct presentation evaluations.

Association of Genetic Technologists Evaluation

Audience: There were approximately 20 genetic technologists in attendance.

Evaluation: AGT conducted its own presentation evaluations.

	Excellent 4	Good 3	Fair 2	Poor 1
Speaker Preparation	9	1	0	0
Level of Seminar	7	3	0	0
Length of Seminar	7	3	0	0
Effective Presentation of Materials	7	3	0	0
Usefulness of Handout Materials	4	5	0	0

What is the most valuable insight gained from this seminar?

- What we do as clinical medicine is a small part of the overall medical system.
- A look at genetics in overall healthcare system.
- The issues of current and future delivery. This was an excellent presentation.
- This should be repeated next year – presented to entire conference attendance in Houston.

- Public perspective, policy and pharmaceutical impact for PGX.
- Impact of personalized medicine.
- The whole lecture was very educational.
- So much information available.
- We need to educate more about genetics.

Will you use information gained in this seminar in your professional position?

Yes: 8 No: 1

What was your main motivation for attending this particular seminar?

- To be educated on how genetics will eventually effect the medical system.
- Clinical background as well as cytogenetics and concerns about how the science reaches the public and how to educate providers.
- To learn more about genetics.
- Topic relevance.
- PGX status.
- Interested in the topic.
- Interest – coevolution of genetics with medicine.
- To be more educated about the field.

Did this seminar meet or exceed your personal goals and expectations?

Yes: 9 No: 0

Why or why not?

- Very thought provoking.
- It was easy to follow along and full of lots of information.

America's Health Insurance Plans Evaluation

Audience: There were approximately 150 managed care executives in attendance.

Evaluation: AHIP conducted a short evaluation:

Both speakers received the same scores (Good is a 3 on a scale of 1 to 4).

Speaker Effectiveness: Good
 Presentation Content: Good
 Value to Organization: Good

American Hospital Association Evaluation

Audience: There were approximately 30 hospital leaders in attendance.

Evaluation: AHA conducted a short evaluation:

Excellent: 2 responses
 Very Good: 5 responses
 Good: 7 responses
 Satisfactory: 1 response

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