Title: Stakeholder Evaluation of the Regional Western States Genetic Services Collaborative

Date: March, 2010

Authors: Jacquie Stock, Kerry Silvey, Lianne Hasegawa, Arthur Yu, Sylvia Au

Background and Purpose

The Western States Genetic Services Collaborative (WSGSC) is one of seven regional genetics services collaboratives in the United States funded as a cooperative agreement by the U. S. Department of Health and Human Services, Health Resources and Services Administration (HRSA). The Regional Collaborative concept was developed by HRSA as a national initiative to improve access and quality in genetic services throughout the United States and territories. The WSGSC includes Alaska, California, Guam, Hawaii, Idaho, Oregon, and Washington. Participants include stakeholders from each state/territory public health genetics program and newborn screening program, family advocates, medical geneticists, genetic counselors, primary care providers, and others working in genetic services or newborn screening. Stakeholders participate in an annual Regional Summit to plan and discuss regional initiatives, and communicate throughout the year via e-mail, telephone conferences, web-based meetings and occasional in-person work group meetings. A Regional Genetics Plan developed by WSGSC stakeholders includes ongoing evaluation of the Collaborative. Stakeholder opinion regarding Collaborative functioning and effectiveness is critical to assuring an optimal regional approach to planning and delivering genetic services, including newborn screening. Herein we report findings from a survey of WSGSC stakeholders designed to measure stakeholder opinion on Collaborative activities and accomplishments.

Methods

Fifty-one stakeholders who attended either the 2008 or 2009 annual WSGSC Regional Summit were e-mailed a request to complete an on-line, self-administered questionnaire available via the web-based application *Survey Monkey*. The questionnaire included thirty-one forced choice, five-point Likert scale questions written by Collaborative Co-Directors and staff and designed to measure stakeholder opinion on Collaborative communication and Collaborative activities related to financing, quality improvement and access to genetic services. The questionnaire also included one open-ended response option seeking qualitative input on Collaborative activities.

Results

Sample

Twenty-five of fifty-one stakeholders completed the survey (response rate=49%). The state with the most respondents was Washington (No.=6). Public health genetics and newborn screening representatives together comprised the largest percent of respondent stakeholder types followed by clinicians (Table 1).

Table 1. Distribution of Western States Genetic Services Collaborative on-line survey respondents by state/territory and stakeholder type.

Primary Stakeholder Type	AK	CA	Guam	HI	ID	OR	WA	Total No.	% Total
Family advocate	1	1		2			2	6	24%
Public health genetics						1	2	3	12%
Public health newborn screening	1			1		2	2	6	24%
Public health genetics + newborn screening			1		1			2	8%
Medical geneticist		2				1		3	12%
Genetic counselor					1			1	4%
Primary care provider	1		1	1				3	12%
Public health nutritionist				1				1	4%
Total No.	3	3	2	5	2	4	6	25	100%
% Total	12%	12%	8%	20%	8%	16%	24%	100%	

Among the twenty-four respondents who reported which years they attended the annual WSGSC Regional Summit, 46% reported participation in both 2008 and 2009, and 29% attended the Summit for all five years it was held (2005-2009). A majority of respondents (No.=18) attended the 2009 Regional Summit (Table 2).

Table 2. Distribution of Western States Genetic Services Collaborative on-line survey respondents by years they attended the annual WSGSC Regional Summit.

Summit Year	No.=24	% Total
2009	18	75%
2007	15	63%
2008	14	58%
2006	8	33%
2005	7	29%
do not know	2	8%

The distribution of survey respondents differed from the distribution of stakeholders to whom a recruiting e-mail was sent (Table3). Medical geneticists were under-represented among survey respondents compared to the number of medical geneticists to whom a recruiting e-mail was sent. Among state representatives, California and Idaho were under-represented among survey respondents compared to those who received a recruiting e-mail. Project Co-Directors and staff did not complete the survey so responses would not be biased based upon funded roles within WSGSC.

Table 3. Distribution of Western States Genetic Services Collaborative on-line survey responders compared to stakeholder composition of the Collaborative.

Stakeholder Type	**% To whom recruiting e-mail was sent No.=51**	**% Respondents No.=25**
Family Representative	24	24
Newborn Screening	24	24
Medical Geneticist	22	12
Primary Care Provider	12	12
Public health genetics	6	12
Public health genetics + newborn screening	4	8
Public Health Other*	8	4
Genetic Counselor	2	4
State Represented		
Washington	20	24
Hawaii	14	20
Oregon	14	16
Alaska	12	12
California	25	12
Idaho	10	8
Guam	6	8

*Nutritionist, Maternal Child Health

Knowledge and Information Sharing in the Collaborative

Knowledge and information sharing is a key goal for the WSGSC. Six of seventeen positively-stated survey statements related to knowledge and information sharing in the Collaborative had a mean response of at least 4.0 or (5=agree, 1=disagree). The remaining eleven statements had a mean response between 3.17 and 3.86 (Table 4). The statements with which the largest majority of respondents agreed related to Collaborative activities resulting in increased dissemination of information; usefulness of informational e-mail notices; increased understanding of facilitators and challenges to regional collaboration; and increased awareness of people or groups in the region who have a stake or interest in genetics.

Table 4. Distribution of responses to Western States Genetic Services Collaborative stakeholder on-line survey statements about knowledge and information sharing in the regional collaborative (5=agree, 1=disagree)
*Total percents may be slightly under or over 100 due to rounding.

Knowledge and Information	No.	% 5 Agree	% 4	% 3	% 2	% 1 Disagree
My opportunities to receive genetics information have increased because of WSGSC activities.	25	52	20	20		8
My opportunities to share genetics information have increased because of WSGSC activities.	25	36	28	24	8	4
WSGSC activities have helped me to routinely exchange genetics information with public health genetics representatives.	25	17	42	21	13	8
WSGSC activities have helped me to routinely exchange genetics information with family representatives.	25	12	40	12	20	16
WSGSC activities have helped me to routinely exchange genetics information with medical geneticists.	25	20	36	24	8	12
WSGSC activities have helped me to routinely exchange genetics information with genetic counselors.	25	4	48	24	12	12
I often read WSGSC WIKI e-mail notices.	25	32	40	16		12
I often read WSGSC e-mail updates.	24	38	42	17		4
I often participate in WSGSC sharing calls.	24	25	29	25	4	17
I often participate in WSGSC work group telephone conferences.	24	17	33	17	17	17
WSGSC WIKI e-mail updates are useful.	24	14	67	10	10	
WSGSC e-mail notices are useful.	25	21	67	4	8	
WSGSC sharing calls are useful.	25	24	48	14	14	
WSGSC work group telephone conferences are useful.	24	20	45	15	15	5
WSGSC communications help me understand successful ways to collaborate within the western region.	25	23	64	5	9	
WSGSC communications help me understand challenges to collaboration within the western region.	25	23	64	5	9	
WSGSC activities help increase my awareness of various people or groups who have a stake or interest in	24	44	36	12	8	

genetics in the western region.						

Financing Genetic Services

Fewer people responded to survey statements about financing genetic services in the region. Statements with the highest means, at least 4.0 (5=agree, 1=disagree), related to learning information about barriers to reimbursement for cognitive genetic services and understanding of financing of genetic services (Table 5). Among twelve respondents who rated a statement related to financing for genetic services in their state, sixty-seven percent agreed at a level of 4 or 5 that health insurance reimbursement for genetic services in their state had improved as a result of WSGSC activities. Among fifteen respondents who rated a statement related to financing for newborn screening in their state, forty-seven percent agreed at a level of 4 or 5 that financing for newborn screening in their state had improved as a result of WSGSC activities.

Table 5. Distribution of responses to Western States Genetic Services Collaborative stakeholder on-line survey statements about financing genetic services and newborn screening in the regional collaborative (5=agree, 1=disagree)

Financing Genetic Services and Newborn Screening	No.	% 5 Agree	% 4	% 3	% 2	% 1 Disagree
Information provided at the 2009 WSGSC Summit increased my understanding of barriers to reimbursement for cognitive genetic services.	22	50	27	9	5	9
Information provided at the 2009 WSGSC Summit increased my understanding of solutions to reimbursement for cognitive genetic services.	21	24	38	33	5	
WSGSC activities increased my understanding of financing of genetic services.	22	32	41	23	5	
WSGSC activities increased my understanding of financing for newborn screening.	22	27	27	32	5	9
Health insurance reimbursement for genetic services has improved in my state as a result of WSGSC activities.	12	42	25	17	17	
Financing for newborn screening in my state has improved as a result of WSGSC activities.	15	33	13	13	13	27

Quality Improvement in Genetic Services

An article describing the *Defining Genetics Services Framework* and *Outcomes for Genetic Services Menu* was published in the *American Journal of Medical Genetics*. [1] Among sixteen respondents who rated the usefulness of information in this article, sixty-three percent assigned a ranking of 4 or 5 (5=agree) to a statement indicating the article was useful to them. Thirty-five percent of twenty respondents assigned a rank of 4 or 5 to a statement indicating they had used the *Defining Genetics Services Framework.* Twenty-eight percent of twenty-one respondents assigned a rank of 4 or 5 to a statement indicating they had used the *Outcomes of Genetics Services Menu(Table 6).*

Table 6. Distribution of responses to Western States Genetic Services Collaborative stakeholder on-line survey statements about genetic services quality improvement in the regional collaborative (5=agree, 1=disagree)

Quality Improvement in Genetic Services	No.	% 5 Agree	% 4	% 3	% 2	% 1 Disagree
The WSGSC article in AJMG about a definition of genetic services and outcomes for genetic services was useful for me.	16	31	31	31	6	
I have used the WSGSC Framework for Defining Genetic Services.	20	5	30	20	5	40
I have used the WSGSC Outcomes of Genetic Services Menu.	21	5	24	33	5	33
Information provided by the WSGSC about other national genetics services quality improvement projects has been useful to me.	21	19	24	33		24

Access to Clinical Genetics Service

Testing use of a regional model to enhance access to genetic services is also a goal of the WSGSC. Among fifteen respondents who ranked the statement "Access to clinical genetics services has improved in my state as a result of WSGSC activities and projects", fifty-three percent ranked the statement with a 4 or 5 (5-agree). Seventy-three percent of twenty-two respondents gave the highest ranking (4 or 5) to a statement indicating WSGSC activities helped them understand barriers to providing clinical genetics services to people who live far from tertiary centers.

Table 7. Distribution of responses to Western States Genetic Services Collaborative stakeholder on-line survey statements about access to clinical genetic services in the regional collaborative (5=agree, 1=disagree)

Access to Clinical Genetic Services	No.	% 5 Agree	% 4	% 3	% 2	% 1 Disagree
WSGSC projects help me understand how to successfully provide clinical genetics services to people who live "far away" from tertiary centers.	21	29	29	33	10	
WSGSC projects help me understand the barriers to providing clinical genetics services to people who live "far away" from tertiary centers.	22	46	27	27		
Access to clinical genetics services has improved in my state as a result of WSGSC activities and projects.	15	33	20	20	20	7

Discussion

The fact that medical geneticists were under-represented among survey respondents compared to the population to whom a recruiting e-mail was sent may indicate that overall findings do not reflect views of region wide medical geneticists which may differ from that of other stakeholders. The population and geographic size of California have been a determining factor in the distribution of funds within the WSGSC. WSGSC funds were distributed so that states with smaller populations and less geographic area may benefit from a regional approach. Strong family participation in both the survey and the Collaborative may indicate family commitment to and comfort level working with the WSGSC.

Information dissemination with the WSGSC seems to be the most appreciated function among survey respondents with informational e-mail notices being the most highly rated. The WSGSC developed a Communication Plan based upon feedback from stakeholders regarding their preference to receive monthly e-mail updates as opposed to a List Serv. Information dissemination about financing and increasing access to clinical genetic services was ranked high among most respondents while Collaborative impact on actual financing for genetic services and newborn screening was ranked lower. The same relationship was true for responses related to access to clinical genetic services. Fewer respondents report finding Collaborative products designed to measure quality improvement useful. Survey responses may reflect the slower pace of achieving measurable accomplishments in regional approaches to improving access and financing for genetics compared to the relative ease of laying the groundwork for understanding these challenges in order to implement solutions.