

EVALUATION PLAN

WESTERN STATES GENETIC SERVICES COLLABORATIVE

Evaluation Period: June 1, 2007 – May 31, 2012

Plan Updated: June 8, 2009

Prepared by:

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INTRODUCTION

Evaluation Goal: The goal of the evaluation is for the Western States Genetic Services Collaborative (WSGSC) and the Maternal Child Health Bureau to understand the efficacy and impact of the Collaborative. The WSGSC will report evaluation findings to the Maternal Child Health Bureau and will use findings to enhance genetic services in the region.

Evaluation Team: Jacquie Stock, MPH, Lianne Hasegawa, MS, CGC; Sylvia Au, MS, CGC; Kerry Silvey, MA, CGC, Practice Model Clinical staff and other grant staff collecting data, WSGSC Steering Committee

Table 1. Roles and Responsibilities of Evaluation Team

Individual and Role	Responsibilities
Jacquie Stock, Evaluator	Provide consultation and direction to the Collaborative on design and implementation of the evaluation. Develop or recommend evaluation instruments, conduct key informant interviews, analyze qualitative data from key informant interviews, analyze Practice Model data, prepare summary reports on overall evaluation findings. Prepare information on evaluation activities for Co-Directors, Collaborative participants and Evaluation Advisory Group.
Kerry Silvey, Co-Director	Direct evaluation development and implementation. Review evaluation summary reports. Submit summary reports to Health Resources and Services Administration. Inform Collaborative participants of evaluation activities and status. Initiate communication with Evaluation Advisory Group regarding evaluation activities.
Sylvia Au, Co-Director	Direct evaluation development and implementation. Review evaluation summary reports. Submit summary reports to Health Resources and

	Services Administration. Inform Collaborative participants of evaluation activities and status. Initiate communication with Evaluation Advisory Group regarding evaluation activities.
Lianne Hasegawa, Genetic Counselor and Grant Coordinator	Participate in evaluation design and implementation as determined by Co-Directors.
Practice Model Clinical staff, other grant staff	Collect and supply data as determined by Co-Directors.
WSGSC Steering Committee	Review and provide input on Evaluation Plan.

STAKEHOLDER ASSESSMENT

Priority stakeholders in the WSGS Collaborative include the following groups from Alaska, California, Guam, Hawaii, Idaho, Oregon and Washington: state public health genetic services and newborn screening workforce; family representatives; genetics specialists including medical geneticists; genetic counselors; metabolic dietitians; and primary care providers. Additional key constituencies are public and private third party payers, allied health professionals, and others. Stakeholder involvement in evaluation planning is described in Table 2.

Table 2. Stakeholder Assessment and Engagement Plan

Stakeholder Category	Role in Evaluation	How and When to Engage
Steering Committee	Review and give input on Evaluation Plan. Review evaluation findings. Recommend modifications to the WSGSC Communication Plan, Evaluation Plan, and Logic Model.	Enable Steering Committee to review evaluation findings by annually posting Practice Model report, key informant interview findings, participants survey results, and other information on WSGSC web site. Annually solicit input from Steering Committee by e-mail and during an in-person meeting or call.
WSGS Collaborative Participants	Complete Regional Summit survey. Complete web-based survey regarding WSGSC activities. Review evaluation findings. Recommend modifications to the WSGSC Communication Plan, Evaluation Plan,	Enable WSGSC participants to review evaluation findings by annually posting Practice Model report, key informant interview findings, participants' survey results, and other information on WSGSC web site. Annually solicit input from Collaborative Participants by e-mail.

	and Logic Model.	
Health Resources and Services Administration	Review annual Evaluation Plan and findings as part of yearly progress reports.	Annual provision of Summary Progress Reports.

FOCUS OF THE EVALUATION

Western States Genetic Services Collaborative Logic Model

The Evaluation Team developed the first WSGSC Logic Model in May, 2007. Substantial revisions were made in early 2009. Co-Directors and WSGSC staff use the Logic Model to guide work and evaluation of the WSGSC. The Evaluation Plan was updated in November, 2008 and April, 2009 by Co-Directors and grant staff. Refer to Appendix 1 for Logic Model.

Stakeholder Needs

WSGSC Co-Directors and Collaborative members will use findings from the evaluation to assess progress of the Collaborative, guide grant activities, and revise or develop new plans to improve regional genetic services. Through evaluation, WSGSC members seek to learn how Collaborative partners view the function and success of the Collaborative, and whether grant goals and objectives are being met.

DATA COLLECTION

See Appendix 2 for detailed Data Collection and Analysis Plan. Table 3, below, shows data sources and responsibilities for collecting, entering, analyzing, summarizing and interpreting and dissemination of findings. Findings will be disseminated to WSGSC (including Steering Committee) and MCHB unless otherwise noted.

Table 3. Data Sources and Responsibilities.

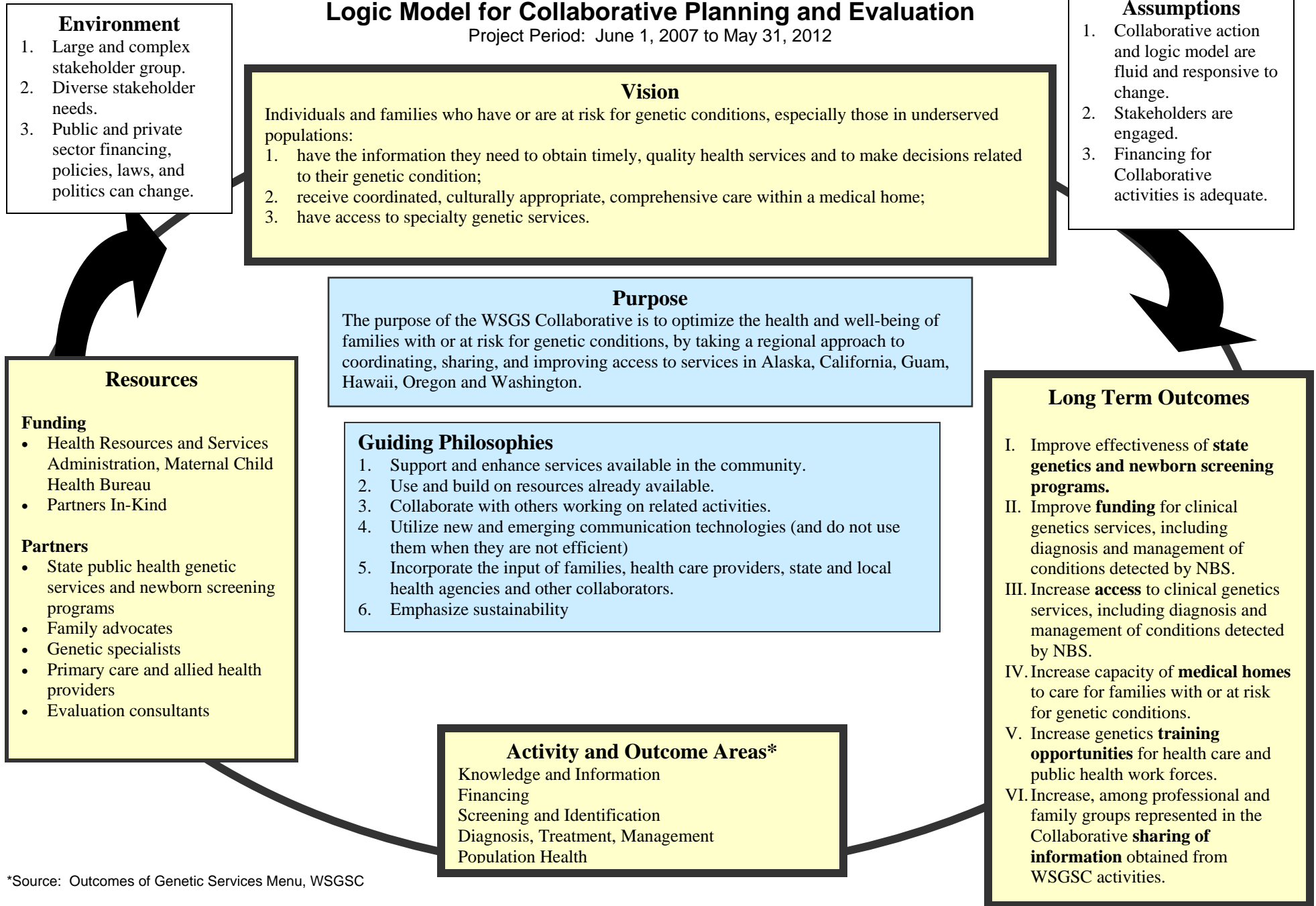
Data Source	Who Collects	Who Enters	Who Analyzes	Who Summarizes and Interprets
Pre-Summit Survey	LH	LH	LH	LH and all
Post-Summit Survey	LH	LH	LH	LH and all
Web-based survey on collaborative activities	JS	JS	JS	JS and all
Public health genetics and newborn screening program leaders key informant interviews	JS	JS	JS	JS and all

Data Source	Who Collects	Who Enters	Who Analyzes	Who Summarizes and Interprets
Hawaii outreach	LH	LH	JS	JS and all
Project descriptive data				
Patient satisfaction data				
Outreach cost data				
Hawaii telehealth	LH	LH	JS	JS and all
Project descriptive data				
Patient satisfaction data				

Idaho outreach	KS	LH	JS	JS and all
Project descriptive data				
Patient & clinic demographic data	AK DOH	AK DOH	JS	JS and all
Outreach cost data				
Oregon-OR telehealth	KS	LH	JS	JS and all
Project descriptive data				
Patient satisfaction data				
Oregon-ID telehealth	KS	LH	JS	JS and all
Project descriptive data				
Patient satisfaction data				
Alaska outreach			JS	
Project descriptive data	KS			
Patient & clinic demographic patient data	AK DOH	AK DOH	JS	JS and all

Western States Genetic Services (WSGS) Collaborative Logic Model for Collaborative Planning and Evaluation

Project Period: June 1, 2007 to May 31, 2012



*Source: Outcomes of Genetic Services Menu, WSGSC

Table 4. WSGSC Logic Model

Activities	Outputs	Short Term Outcomes 2009-2011 awareness, knowledge, beliefs, attitudes	Medium Term Outcomes 2012-2014 behavior, practice, policies
Knowledge and Information			
All Stakeholders			
<ol style="list-style-type: none"> 1. WIKI E-mail notices 2. E-mail updates 3. Meetings (in-person, telephone, webinar) 4. Website maintenance 5. Annual Regional Summit 6. Plan and submit articles, presentations, trainings 7. Annual update of Regional Plan: Logic Model, Evaluation Plan, Communications Plan, Work Plan. 8. Collect and submit NCC Evaluation data. 9. Write and submit annual grant Progress Report to MCHB. 10. Respond to MCHB and NCC information requests. 11. WSGSC participation in and connection with national work groups and projects: NSTRN, ACHDNC, NCC committees and work groups (Disaster Preparedness, Telemedicine, Adolescent Transition, Long Term FU/Data Collection). Principal Investigators participate in National committees and meetings such as ACHDNC meetings. 12. Recruit and retain diverse stakeholders from Guam, AK, CA, HI, ID, OR, WA. (Stakeholders: public health genetics and newborn screening, medical geneticists, genetic counselors, family advocates, primary care providers, third party payers) 	<ol style="list-style-type: none"> 1-5. Record of E-mails, meetings, web updates, Summit 6. Publications, presentations, trainings records 7. Evaluation Plan 8-9. Progress Report with evaluation findings 10. NCC Evaluation reports 11-12. Meeting and work group records 	<ol style="list-style-type: none"> A. WSGSC stakeholders have increased opportunities to share or receive genetics related information as a result of WSGSC activities. B. WSGSC stakeholders increase their awareness of who other stakeholders are throughout the region and the roles stakeholders play in genetic services. C. Information sharing between WSGSC and other regions, and the WSGSC and NCC committees is increased. 	<ol style="list-style-type: none"> M. WSGSC representative disseminate information from Collaborative activities to their respective constituent groups.

People Impacted by Genetic Conditions			
<p>13. Link web-site resources between WSGSC and F2F HICs.</p> <p>14. WSGSC staff and family representatives provide technical assistance to states submitting F2F HIC grant applications.</p> <p>15. Create and disseminate to parents and individuals with CPT1a deficiency and AK PCPs a DVD about CPT1a deficiency.</p>	<p>13. Web-site resources</p> <p>14. Completed grants</p> <p>15. DVD, dissemination plan</p>	<p>D. People impacted by genetic conditions have access to information about genetic resources.</p> <p>E. Parents of children with CPT1a deficiency and individuals with CPT1a deficiency have increased knowledge about their condition.</p>	<p>N. Public health genetic services agencies, genetic specialty leaders and family organizations routinely exchange information about genetic resources.</p>
Health Care Providers			
<p>16. Create and disseminate to parents and individuals with CPT1a deficiency, and AK community health aids, a DVD about CPT1a deficiency.</p>	<p>16. DVD, dissemination plan</p>	<p>F. Community health aids in AK have increased knowledge about screening, diagnosis and treatment of people with or at risk for genetic conditions.</p>	
Financing			
Insurance			
<p>17. Hawaii Genetics staff will meet with Guam health insurers to document need for reimbursement for genetic testing.</p> <p>18. Collect and analyze WA data about billing and reimbursement for cognitive genetic services and disseminate results.</p>	<p>17. Meeting record</p> <p>18. Report of findings, dissemination plan</p>	<p>G. WSGSC stakeholders have an increased understanding of barriers and solutions to improved reimbursement for genetic services.</p>	<p>O. Health insurance reimbursement for genetic services in the region is improved.</p>

Quality Improvement			
Genetic Services			
19. Identify a small number of measurable outcomes and indicators that state genetic programs can use to evaluate their programs. 20. WSGSC collaborators contribute to development of the Region IV/ACMG genetics services QI tool.	19. Post list on WSGSC web site. 20. Documentation and description of WSGSC staff participation in developing the Region IV/ACMG QI tool.	H. WSGSC members have increased access to information about current thought in measuring impact or quality of genetic services.	P. Increase in the number of western states public health genetic services programs that measure outcomes to evaluate the effectiveness of their program. Q. Increase quality improvement activities in state genetics and newborn screening programs.
Screening and Identification			
Newborn Screening, Maternal Serum Screening			
21. NBS Test Value Cut-Off Meeting 22. Develop Regional NBS Emergency Response Plan.	21-22. Meeting records 22. Regional NBS Emergency Response Plan		R. Regional public health genetics and newborn screening services are improved or expanded as a result of WSGSC activities. S. Increase the number of states/territory that carry out genetics services and/or NBS contingency planning activities.
Diagnosis, Treatment, Management			
Medical Home			
23. Create and disseminate portable medical record template.	23. PMR template, dissemination plan	I. Families and primary care providers in the western region have access to a portable medical record template.	
Access to Specialty Genetic Services			
24. Honolulu medical geneticist and genetic counselor provide in person genetics visits to HI neighbor islands. 25. Idaho Outreach - OR medical geneticist and dietician provide in person genetics visits to ID PKU clinics in towns other than Boise.	24-28. Services and description	J. WSGSC participants have an increased understanding of the issues related to increasing access to genetics services for rural populations. K.. AK Department of Health has information it needs to decide where to locate outreach genetics and metabolic	T. Public health leaders and genetic specialists in the WSGSC region use information from WSGSC activities to plan and implement programs to improve access to specialty

<p>26. Honolulu medical geneticist and genetic counselor provide genetics visits via interactive video- conference to patients on HI neighbor islands.</p> <p>27. Portland medical geneticist and genetic counselor provide services via interactive video-conference to patients in OR towns.</p> <p>28. Provide financial support for AK genetics and metabolic clinic coordinator to attend outreach clinics.</p>		<p>clinics.</p> <p>L. Hawaii Department of Health and Hawaii Community Genetics collaborators have the information to strategically plan and implement the number and type of clinical genetic services required to provide statewide access to genetic services in a timely manner.</p>	<p>genetic services.</p> <p>U. Increase proportion of the Guam and HI populations that lives within two hours transportation time of a visit with a pediatric genetics specialist.</p> <p>V. Maintain proportion of the ID population that lives within a 2 hour drive of a visit with a metabolic genetics specialist.</p> <p>W. Maintain proportion of the AK population that [population-based measure geographic access measure] with a genetics specialist.</p>
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Table 5. WSGSC Logic Model—Indicators and Data Sources

Short Term Outcome 2009-2011 awareness, knowledge, beliefs, attitudes	Indicator measure of outcome	Medium Term Outcome 2012-2014 behavior, practice, policies	Indicator measure of outcome
Knowledge and Information			
All Stakeholders			
A. WSGSC stakeholders have increased opportunity to share or receive genetics related information as a result of WSGSC activities. B. WSGSC stakeholders increase their awareness of who other stakeholders are throughout the region and the roles stakeholders play in genetic services. C. Information sharing between WSGSC and other regions, and the WSGSC and NCC committees is increased.	Description of number and type of information sharing opportunities resulting from WSGSC activities (WSGSC records) % of WSGSC stakeholders who report WSGSC Evaluation findings helped them understand challenges and success to regional collaboration for genetic services (on-line survey)	M. WSGSC representative disseminate information from Collaborative activities to their respective constituent groups.	% of WSGSC key stakeholders reporting they use WSGSC generated information (on-line survey, key informant interviews)
People Impacted by Genetic Conditions			
D. People impacted by genetic conditions have access to information about genetic resources. E. Parents of children with CPT1a deficiency and individuals with CPT1a deficiency have increased knowledge about their condition.	% of F2F websites in the region that link to WSGSC list of family resources or that include list on their website. ID and AK applicants for F2Fs requesting assistance with applications receive help. % of parents who report increased knowledge about CPT1 after viewing DVD (post viewing evaluation form)	N. Public health genetic services agencies, genetic specialty leaders and family organizations routinely exchange information about genetic resources.	Extent to which stakeholders agree with survey statement related to sharing resources (on-line survey)

Health Care Providers			
F. Community health aides in AK have increased knowledge about screening, diagnosis and treatment of people with or at risk for genetic conditions.	Number of AK community health aids reporting increased understanding of CPT1A deficiency (post training session survey)	[To be determined]	[To be determined]
Financing			
Insurance			
G. WSGSC stakeholders have an increased understanding of barriers and solutions to improved reimbursement for genetic services.	<p># of Guam third party payers reporting to HI public health leaders they will implement reimbursement for genetic testing.</p> <p>% of WSGSC stakeholders reporting increased understanding of barriers and solutions to reimbursement for cognitive genetic services (on-line survey).</p>	O. Health insurance reimbursement for genetic services in the region is improved.	<p>Increase in the number of Guam third party payers that pay for genetic tests ordered during WSGSC Guam outreach & telemedicine visits.</p> <p>% of WSGSC stakeholders who affirm reading WSGSC reports related to reimbursement (on-line survey)</p> <p>Description of how WA state Genetics Services Section used reimbursement project results to improve reimbursement for genetics services.</p>
Quality Improvement			
Genetic Services			
H. WSGSC members have increased access to information about current thought in measuring impact or quality of genetic services.	<p>% of WSGSC stakeholders who report reading information about outcomes and QI disseminated by WSGSC (on-line survey and key informant interviews)</p> <p>Description of how Region IV QI tool is disseminated to WSGSC</p>	<p>P. Increase in the number of western states public health genetic services programs that measure outcomes to evaluate the effectiveness of their program.</p> <p>Q. Increase quality improvement activities in state genetics and newborn screening programs.</p>	# of public health programs that use one or more of the WSGSC outcomes and indicators to evaluate their programs

Screening and Identification			
Newborn Screening, Maternal Serum Screening			
		<p>R. Regional public health genetics and newborn screening services are improved or expanded as a result of WSGSC activities.</p> <p>S. Increase the number of states/territory that carry out genetics services and/or NBS contingency planning activities.</p>	<p>Description of how CA, WA, and NWRNWP used information from the meeting to improve their programs (key informant interviews or on-line survey three months after meeting (~7-3-09)</p> <p>Number of WSGSC states/territory that adopts Regional NBS Emergency Response Plan</p>
Diagnosis, Treatment, Management			
Medical Home			
I. Families and primary care providers in the western region have access to a portable medical record template.	Portable medical record template completed and description of dissemination plan	[To be determined]	[To be determined]
Access to Specialty Genetic Services			
<p>J. WSGSC participants have an increased understanding of the issues related to increasing access to genetics services for rural populations.</p> <p>K. AK Department of Health has information it needs to decide where to locate outreach genetics and metabolic clinics.</p> <p>L. Hawaii Department of Health and Hawaii Community Genetics collaborators have the information to strategically plan and implement the number and type of clinical genetic services required to provide statewide access to genetic services in a timely manner.</p>	% of WSGSC participants that report an increased understanding of issues related to delivery of genetics services "far away" from tertiary genetics centers (on-line survey)	<p>T. Public health leaders and genetic specialists in the WSGSC region use information from WSGSC activities to plan and implement programs to improve access to specialty genetic services.</p> <p>U. Increase proportion of the Guam, HI, and OR populations that lives within two hours transportation time of a visit with a pediatrics genetics specialist.</p> <p>V. Increase proportion of the ID population that lives within a 2 hour drive of a visit with a metabolic genetics specialist.</p>	<p>Description of how Practice Model evaluation findings are disseminated and reviewed at least annually by WSGSC public health programs and specialists, and used to revise clinical activities</p> <p>Proportion of WSGSC state genetics and metabolic program representatives that report using findings from the WSGSC practice model to plan, implement, or evaluate their program's clinical services (key informant interviews)</p> <p>AK state genetics program staff report using findings from clinic coordinator assessment to</p>

		<p>W. Increase proportion of the ID population that lives within a 2 hour drive of a visit with a metabolic genetics specialist.</p>	<p>decide locations of AK outreach clinics (key informant interview with AK CYSHN manager)</p> <p>Proportion of the Guam, HI, and OR populations that lives within an approximately two hour drive of a genetics clinic, outreach clinic location or telemedicine site.</p> <p>Proportion of the ID population that lives within an approximately two hour drive of a metabolic clinic or outreach metabolic clinic site.</p>
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Appendix 2

2009 WSGSC Practice Model Evaluation and Data Analysis Plan

Create one database combining project description and satisfaction data or assure that descriptive variables for site, visit, and other are in each separate database.

PROJECT DESCRIPTIVE DATA

Calculate frequencies for the variables described below.

2009 Funded Projects	Description	Visit Type (OR vs. TH)	Visit Type (FU vs. Initial)	Pt. ID No. (To enable Pt. vs. Visit Count)	Visit Site	Visit Date	Pt. Age at Visit	Pt. Ethnicity	Dx (ICD9 code?)	Referral Reason	Personnel Type at Pt. Site	Personnel Type at Tertiary Site
Hawaii outreach	Honolulu MG + GC travel to Hilo, Maui, Kauai, Molokai											
Hawaii telehealth	Honolulu MG + GC, Pt + PHN Hilo, Maui, Kauai, Molokai											
Idaho-Oregon outreach	Portland MG + DT travel Boise, PKU Pt + GC		No	?	Y	Y	Y	?	?	?	?	
Idaho-Oregon telehealth	Portland MG + DT, urgent Pt + GC Boise											
Oregon telehealth	Portland MG + GC, Genetic + Metabolic Pt + PHN, Medford											
Alaska outreach	Anchorage PH Coord travels to Alaskan sites											

PROJECT COST DESCRIPTIVE DATA

Calculate cross-tabs for air, car, meal and hotel cost by site for outreach projects by site

2009 Funded Projects	Description	Clinic Site	No. Pts Seen	Total \$ Air	Total \$ Meal	Total \$ Car	Total \$ Hotel
Hawaii outreach	Honolulu MG + GC travel to Hilo, Maui, Kauai, Molokai						
Oregon outreach	Portland MG + DT travel Boise, PKU Pt + GC						
Alaska outreach	Anchorage PH Coord travels to ?						

PROJECT SATISFACTION DATA

Calculate response rate

Calculate frequencies for the variables described below.

Calculate crosstabs for Pt. satisfaction key variables by site

		Pt. Satisfaction					

		No. Offered Survey	Respondent Relation to Pt.	Respondent Demographics?	Visit Type	Visit Site	Etc. as above
2009 Funded Projects	Description						
Hawaii outreach	Honolulu MG + GC travel to Hilo, Maui, Kauai, Molokai						
Hawaii telehealth	Honolulu MG + GC, Pt + PHN Hilo, Maui, Kauai, Molokai						
Oregon outreach	Portland MG + DT travel Boise, PKU Pt + GC						
Oregon telehealth	Portland MG + DT, urgent Pt + GC Boise						
Oregon telehealth	Portland MG + GC, Genetic + Metabolic Pt + PHN, Medford						
Alaska outreach	Anchorage PH Coord travels to ?						