



Regional Genetic Services Practice Model Evaluation

**Report on delivering genetic services via
outreach and telehealth in Guam and the western
states**

February 2009

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Summary Conclusions

In Guam and the six states in the western region (Alaska, California, Hawaii, Idaho, Oregon and Washington), genetic specialty providers are located primarily in tertiary centers in California, Honolulu, Portland and Seattle. California has the largest number of practicing medical geneticists and genetic counselors, yet California did not participate in the regional model due to the vast size and population in their state and the limited amount of funding available for the entire region. Through Collaborative Director-led initiative, public health agencies in the remaining participating states formed partnerships with specialty clinicians working in private, non-profit tertiary centers to provide genetic consultation via outreach or inter-active telehealth visits. The process of planning and negotiating which specialists provided services to what areas is an example of successful regional collaboration for the involved states and territory. Service delivery models varied state to state because the health service delivery system is different in each state and the number and type of genetic specialists and where they practice also differs from state to state.

We found that patients were generally satisfied with the genetic services they received via outreach or telehealth visits. The proportion of patients who reported they would prefer to travel to see a specialist in-person was different for patients in Hawaii compared to patients in Oregon. Though not specifically detailed herein, we also found that providers express general satisfaction with offering genetic services via outreach and telehealth visits, if they have time available in their schedule to add either travel time or additional patients.

The most useful regional practice models to increase access to genetic services for people who live far from specialists vary from state to state depending upon several factors:

- What public-private partnerships can be developed and sustained
- The distance required for travel and the rising cost of travel compared to personnel, equipment and technical costs for delivery of telehealth
- What portion of costs for either travel or telehealth, not paid with public grant funds, can be paid by partnering organizations
- Commitment or availability of medical geneticists and genetic counselors to provide additional services in ways other than patient visits at their immediate work site

At the October 2008 Regional Summit of the Western States Genetic Services collaborative, in discussing the above factors related to sustaining differing practice models, experts made the additional point that in light of the above, re-thinking who can deliver genetic services is an additional approach that should be explored. The experts raised questions about how primary care providers or nurses may be trained to deliver some genetic services in order to improve access based upon lack of genetic specialty human resources. Over the next year, the Western States Genetic Services Collaborative will continue to explore how best to sustain improved access to genetic services in the region.

Background

The Practice Model, comprised of several projects throughout the western region, is an initiative of the Western States Genetic Services Collaborative (WSGSC). The purpose of the initiative is to increase access to genetic services for westerners who live far from genetic specialty providers including genetic counselors, medical geneticists and dietitians. Projects within the initiative offered an opportunity to test and demonstrate provision of medical genetic consultations, genetic counseling, or specialty dietitian services via outreach and telehealth visits. The WSGSC demonstrated and evaluated this regional practice model with funds from the Health Resources and Services Administration (HRSA). This report describes projects within the Practice Model and reports on evaluation findings for grant periods June 1, 2005 through May 31, 2008.

Description of the Practice Model

Guam and all states in the western region except California participated in genetic service delivery models of either outreach or telehealth visits as shown in Figures 1 and 2. Visits are defined as a health care provider or providers participating in a session with a family. Outreach visits involved genetic providers traveling to communities remote from urban centers. In this report we use the term telehealth to refer to visits provided via interactive telehealthconferencing.

Figure 1. Genetic services provided via outreach trips from western urban centers to non-urban sites.

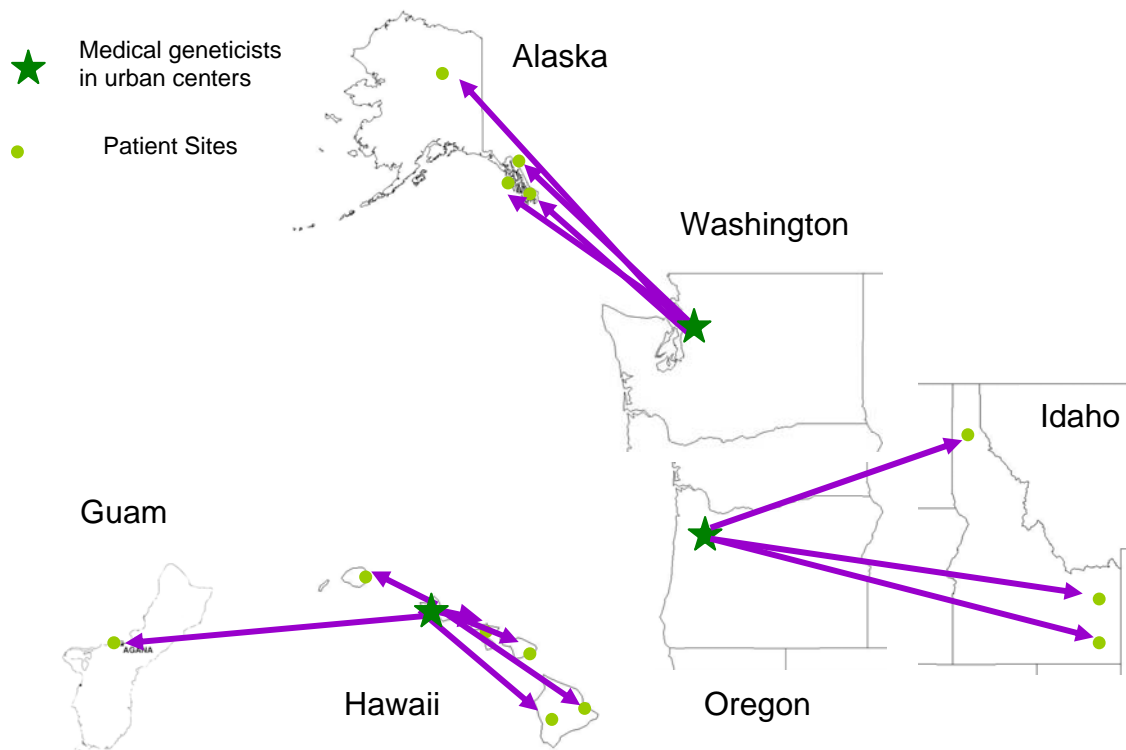
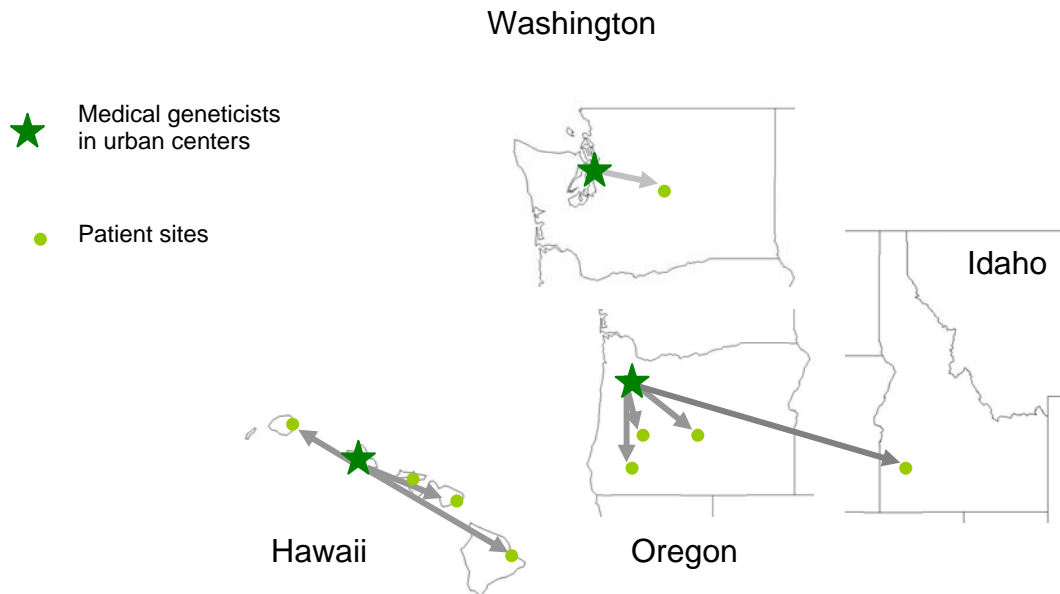


Figure 2. Genetic services provided via telehealth from western urban centers to non-urban sites.



WSGSC contributed at least partial funding for salary and/or travel costs in both outreach and telehealth projects as shown in Table 1. Participating partners paid for all other costs to deliver the services.

Table 1. WSGSC funding* for outreach and interactive-telehealth visits by patient and specialty sites

	Outreach	
	Patient Site	WSGSC\$*
Honolulu to Hilo, Maui, Kona, Waimea, Kauai, Molokai	MG + GC	salary + travel
Honolulu to Guam	MG + GC	salary + travel
Portland to Lewiston, Idaho Falls, Coeur d'Alene	MG + DT	salary + travel
Seattle to Anchorage, Juneau, Ketchikan, Fairbanks, Sitka	MG + GC	travel

	Telehealth		
	Specialty Site	Patient Site	WSGSC\$*
Between Honolulu and Hilo, Kauai, Maui	MG + GC	SW**	salary
Between Portland and Boise	MG + DT	GC**	salary
Between Portland and Bend, Medford	MG + DT	PHN**	salary
Between Seattle and Yakima, Washington	MG	GC	salary

*WSGSC supplied at least partial funding

MG – medical geneticist

GC – genetic counselor

DT – dietitian

SW** – social worker, not funded by WSGSC

GC** - genetic counselor not funded by WSGSC

PHN** – public health nurse, not funded by WSGSC PHN was paid for

Evaluation Areas and Data Collection

To evaluate the Practice Model initiative, WSGSC Co-Directors, staff and clinicians collected data in the following areas:

- Project process
- Visit and patient characteristics
- Family and provider satisfaction
- Provider time and travel costs
- Family time and travel costs

This report includes findings in all areas except provider satisfaction and family time and costs which will be covered in future publication.

Hawaii and Washington state projects submitted applications to relevant Institutional Review Boards (IRB) to apply for protection of human subjects. The Institutional Review Boards classified both Hawaii and Washington state projects as quality-improvement projects for business purposes, not research. Project staff and clinicians supplied information about processes of the various projects to Collaborative Co-Directors and the evaluator. Immediately after patient visits, a genetic counselor, social worker or public health nurse offered each family the opportunity to complete a written, self-administered questionnaire containing questions related to satisfaction about the visit. Providers completed written, self-administered questionnaires following visits. Project staff and clinicians estimated time and reported travel costs for both outreach and interactive telehealth projects.

Hawaii-Guam Findings

The Hawaii Practice Model project included a combination of outreach and telehealth. A medical geneticist and genetic counselor traveled to Guam and to Hawaii neighboring islands. For telehealth visits, a medical geneticist and genetic counselor provided consultation to patients on neighboring islands. Among 312 patient visits in the Hawaii Practice Model project, 95% were outreach visits.

In the Hawaii outreach project, excluding Guam visits, between June 2005 and May 2008, a majority (57%) of genetic consultations were at Hilo (35%) and Maui (21%). (See Table 2)

Table 2. Number of Hawaii outreach clinics and visits by site and grant year

Clinic Location	No. Patients 2005-2006	No. Patients 2006-2007	No. Patients 2007-2008	Total Patient Visits 2005-2008	% of All Patients	Average Patient Visits/Clinic
Hilo	8	36	35	79	36.07%	7.18
Maui	8	21	16	45	20.55%	7.50
Kona + Waimea	0	14	23	37	16.89%	12.33
Kauai	7	14	13	34	15.53%	6.80
Kona	7	5	3	15	6.85%	5.00
Molokai	0	4	5	9	4.11%	4.50
Total	30	94	95	219	100.00%	

	No. Clinics 2005-2006	No. Clinics 2006-2007	No. Clinics 2007-2008	Total No. Clinics 2005-2008	% of All Clinics 2005-2008
Hilo	1	5	5	11	36.67%
Maui	1	3	2	6	20.00%
Kauai	1	2	2	5	16.67%
Kona + Waimea (2 day)	0	1	2	3	10.00%
Kona	1	1	1	3	10.00%
Molokai	0	1	1	2	6.67%
Total	4	13	13	30	100.00%
Average No. Patients/Clinic	8	7	7	7	

The number of patients who received a telehealth visit in the Hawaii project decreased from eight in the first year of the program to four visits during the 2007-2008 project period. (See Table 3)

Table 3. Number of patients receiving genetic consultation via telehealth by location of patient site

Patient Site	No. Patients 2006-2007	No. Patients 2007-2008	Total No. Patients 2006-2008
Hilo	3	3	6
Kauai	5	0	5
Maui	0	1	1
Total	8	4	12

Hawaii Patient Visit Characteristics

Slightly over one third of patients seen in Hawaii outreach visits were less than three years of age. Sixty-one percent of patients were less than six years of age.

Table 4. Distribution of age of patients in Hawaii outreach visits

Age Group	No.	%
0-2 years	29	36%
3-5 years	20	25%
6-12 years	18	23%
13-18 years	9	11%
>18 years	4	5%
	80	100%

Hawaii Outreach Visit Patient Diagnoses

Diagnosis information is available for patients in thirty-five Hawaii outreach visits. Three patients had more than one diagnosis or presenting symptom. Thirty-five of the 219 patients evaluated at a Hawai'i outreach clinic had diagnoses made prior to the clinic or as a result of the clinic. The diagnoses were varied and ranged from chromosomal conditions and single gene disorders to metabolic conditions and disorders of dysmorphology.

Hawaii Personnel Time

For all project years, the genetic counselor worked the highest number of hours in outreach visits before and after consultations. The genetic counselor and medical geneticist worked the same number of hours during outreach visits. For all grant periods, genetic counselor hours comprised 52% percent of total hours expended. Table 9 shows increasing number of outreach hours each project year and the estimated proportion of personnel hours devoted to travel. The estimated number of hours spent before outreach clinics was based upon the number of patients projected to attend the clinic, not the actual number that ultimately attended, so number of hours per patient reported here is higher than the true number of hours would be because of "no-shows" to clinic. In Hawaii outreach visits, the number of personnel hours per patient visit increased each year with a total of fourteen personnel hours per patient in the most recent project period.

Table 5. Estimated number of personnel hours for Hawaii outreach and telehealth visits by project period.

	No. Hours 2005-2006	No. Hours 2006-2007	No. Hours 2007-2008	Total Hours 2005-2008
Estimated total outreach travel hours	31	109	116	256
Estimated total telehealth travel hours	0	0	0	0
Total all outreach personnel hours*	369	1240	1328	2937
Total all telehealth personnel hours**	0	82	42	124
No. planned outreach patient visits	30	94	95	219
No. planned telehealth patient visits	0	8	4	12
No. personnel hours/planned outreach patient visits	12	13	14	13
No. personnel hours/planned telehealth patient visits	0	10	11	10
Proportion of outreach hours that are travel	8%	9%	9%	9%

*genetic counselor, medical geneticist, on-site facilitator, administrative assistant

**genetic counselor, medical geneticist, dietitian, on-site facilitator, administrative assistant

Table 6 shows the average number of personnel travel hours by site for Hawaii outreach visits. The two-day trips to Kona and Waimea had the highest average number of patient visits per trip and the highest average number of travel hours per trip.

Table 6. Average number of personnel travel hours per trip by site for Hawaii outreach visits.

Site	No. Trips	No. Patients	Average No. Patients/Trip	Total Travel Hours	Average No. Travel Hours/Trip
Molokai	2	9	5	12	6
Kauai	5	34	7	34	7
Maui	6	45	8	42	7
Kona	3	15	5	24	8
Hilo	11	79	7	101	9
Kona + Waimea, 2-day trip	3	37	12	42	14
Totals	30	219	43	255	8

During the combined two year periods in which genetic consultations were offered via telehealth, genetic counselor hours comprised 44% of all personnel hours and medical geneticist hours comprised 29%. (See Table 7)

Table 7. Estimated number of personnel hours spent for Hawaii telehealth visits by provider type and project period

Time Period	Genetic Counselor	Medical Geneticist	Dietitian	Administrative Assistant	On-Site Facilitator
2006-2007					
Before Visits	12	4	2	1	1
During Visits	9	10	1	0	10
After Visits	12	12	4	0	4
Total 2006-2007	33	26	7	1	15
2007-2008					
Before Visits	8	2	0	1	1
During Visits	5	4	0	0	5
After Visits	8	4	0	0	4
Total 2007-2008	21	10	0	1	10

Hawaii Personnel Travel Costs

Personnel travel costs for Hawaii outreach visits increased over the three grant periods from June 2005 through May 2008, with air fare comprising 64% of total costs for all three grant periods. (Table 8) Personnel travel cost per patient visit in Hawaii outreach visits increased each year with a travel cost of \$52/patient visit in the most recent grant period. (Table 9)

Table 8. Personnel travel costs for Hawaii outreach visits by provider type and project year

Type of Cost	Cost 2005-2006	Cost 2006-2007	Cost 2007-2008	Total Cost 2005-2008
Medical geneticist meals	\$120	\$420	\$390	\$930
Medical geneticist air fare	\$410	\$996	\$1,652	\$3,058
Medical geneticist parking	\$40	\$140	\$140	\$320
Genetic counselor meals	\$120	\$420	\$390	\$930
Genetic counselor airfare	\$410	\$1,080	\$1,652	\$3,142
Genetic counselor parking	\$40	\$130	\$120	\$290
Car rental	\$60	\$199	\$251	\$510
Miles charge	\$13	\$41	\$57	\$111
Hotel	\$0	\$100	\$300	\$400
Hotel Package	\$0	\$5	\$15	\$20
Total Cost	\$1,213	\$3,531	\$4,967	\$9,711

Table 9. Personnel travel cost per patient visit in Hawaii outreach visits by year

	2005-2006	2006-2007	2007-2008	Total 2005-2008
Number of visits	30	94	95	219
Personnel travel cost	\$1,213	\$3,531	\$4,967	\$9,711
Personnel travel cost per patient visit	\$40.43	\$37.56	\$52.28	\$44.34

Table 10. Estimated average personnel travel cost per patient by site in Hawaii outreach project for 2006-2008.

Site	No. Patients	2006-2007	2007-2008	Total	Average Cost/Patient
Kona	8	\$296	\$482	\$778	\$97
Molokai	9	\$404	\$390	\$794	\$88
Kona + Waimea	37	\$484	\$1,222	\$1,706	\$46
Kauai	27	\$480	\$660	\$1,140	\$42
Maui	37	\$774	\$713	\$1,487	\$40
Hilo	71	\$1,093	\$1,499	\$2,592	\$37
Total	189	\$3,531	\$4,966	\$8,497	\$45

Hawaii Family Satisfaction—Outreach Visits

The response rate to the family satisfaction survey among families who received an outreach visit was 68% (165/244). At least 95% of all respondents either agreed or strongly agreed with positive statements about communication, quality of care, and privacy aspects of outreach visits.

Table 11 . Distribution of responses to Hawaii outreach family satisfaction survey.

	% Strongly Agree	% Agree	% Disagree	% Strongly Disagree	% NA	No.
Family Satisfaction						
information received before visit was helpful	51.5	41.2	1.8		5.5	165
staff introduced selves, described role	69.1	29.1	1.2		0.6	165
good conversation with specialist	75.9	23.5	0.6			166
specialist listened to information I provided	76.4	23	0.6			165
specialist responded to my questions	73	24.8	0.6		0.6	165
privacy protected	67.1	30.5	0.6		1.8	165
Family Satisfaction						
confident in quality of care	76.4	23	0.6			165
confident in clinic recommendations	77.4	22	0.6			164
would recommend outreach clinic to others	77.6	21.8	0.6			165
satisfied with visit	78.8	20.6	0.6			165
prefer outreach clinic to traveling	20.9	14.7	39.3	19	6.1	163
would come to outreach clinic again	78.2	20.6	1.2			165

Table 12 shows the percent of respondents to Hawaii outreach family satisfaction surveys who answered Yes or No to questions related to challenges to traveling for an outreach visit. Twenty-five percent reported they would not have received needed care for their child if they had not come to the outreach visit.

Table 12. Distribution of responses to Hawaii outreach family satisfaction survey—“Before today’s visit, what made it hard to get the specialty services your child needs?”

Family opinion No.=170	% Yes	% No
hard to pay for child care	77	23
costs too much to travel	57	44
miss work and wages	44	56
see local provider	31	69
not have gotten care my child needed	25	75
costs too much (insurance)	18	82
other	14	86
large hospital uncomfortable	11	89

Hawaii Family Satisfaction—Telehealth Visits

Information about demographic characteristics of family satisfaction survey respondents was not collected in Hawaii projects. The response rate to the family satisfaction survey among families who received a telehealth visit was 83% (10/12). At least 95% of all respondents either agreed or strongly agreed with positive statements about communication, quality of care, equipment and privacy aspects of telehealth visits. Fifty percent of respondents either agreed or strongly agreed with the statement “Despite the obstacles to receiving care in person, I would still prefer to travel to see the specialist.” While 80% checked Yes to the statement “it costs too much to travel”, as a reason for what made it hard to get specialty services. (See Tables 13 and 14)

Table 13. Distribution (percent) of responses to Hawaii telehealth visit family satisfaction survey

Family Satisfaction No.=10	Strongly Agree	Agree	Disagree	Strongly Disagree	Missing or NA
information received before visit was helpful	40	50	10		
staff introduced selves, described role	90	10			
good conversation with specialist	50	40			10
specialist listened to information I provided	70	30			
specialist responded to my questions	70	30			
privacy protected	60	40			
confident in quality of care	60	40			
confident in clinic recommendations	60	40			
would recommend telehealth to others	80	20			
satisfied with visit	80	20			
prefer traveling to telehealth	10	40	50		
would come to telehealth again					100
staff could work equipment	30	20			50
equipment worked well	60	40			

Table 14. Distribution of responses to Hawaii telehealth visit family satisfaction survey—“Before today’s visit, what made it hard to get the specialty services your child needs?”

Family Satisfaction	No.=10	No. Yes	No. No
costs too much to travel		8	2
other		6	4
If had not been able to use telehealth today, would have traveled to Honolulu		4	1
miss work and wages		2	8
If had not been able to use telehealth today, would have seen local provider		2	3
hard to pay for child care		1	9
costs too much (insurance)		1	9
large hospital uncomfortable		1	9
If had not been able to use telehealth today, would have waited until specialist came near my home		1	4
If had not been able to use telehealth today, would have not received services		1	4
not have gotten care my child needed		0	0

Oregon-Idaho Findings

The Oregon-Idaho Practice Model projects included both outreach and telehealth. For outreach visits, a medical geneticist and dietitian traveled from Portland to Idaho Falls and Coeur d’Alene. Telehealth visits involved a Portland medical geneticist and dietitian consulting to a patient on-site with a genetic counselor in Boise, Idaho and to a patient on-site with a public health nurse in Bend and Medford, Oregon.

Oregon Visit Description—Telehealth Visits

The number of patients who received genetic consultations via telehealth increased over the past three grant years with a high of thirty-six patients in the most recent period. The average number of patients seen in one day increased from 1.17 the first year to 1.71 in the most recent grant year. Of forty-three clinics held, sixty percent consisted of one patient visit. In four of sixty-four visits an interpreter was present. (See Tables 15-17)

Table 15. Number of Oregon telehealth visits per day, 2005-2008

	2005-2006	2006-2007	2007-2008	Total
No. visits	7	21	36	64
No. *clinics	6	16	21	43
No. visits/clinic	1.17	1.31	1.71	1.49

*Clinic refers to visits provided on same day

Table 16. Distribution of number of visits per clinic day for Oregon telehealth visits, 2005-2008

No. of Patients per Clinic	No. of Clinics	% of Clinics
3	4	9.30%
2	13	30.23%
1	26	60.47%
	43	100.00%

Table 17. Distribution of patient site in Oregon telehealth visits, 2005-2008

Location	No. Patients	% Patients
Bend	26	41%
Medford	25	39%
Eugene	8	13%
Boise, Idaho	5	8%
Total	64	100%

Medical geneticists participated in 84% of consultations, genetic counselors participated in 45%, and dietitians participated in 20%. (See Table 18)

Table 18. Number and percent of telehealth visits by type of provider participating in the visit

Provider Type	No.	%
Medical geneticist + genetic counselor	25	39.06%
Medical geneticist	21	32.81%
Medical geneticist + dietitian	7	10.94%
Genetic counselor	4	6.25%
Dietitian	4	6.25%
Two dietitians	2	3.13%
Two medical geneticists	1	1.56%
Total	64	100.00%

Oregon Patient Visit Characteristics—Telehealth Visits

Visits for patients with metabolic conditions and other genetic conditions were evenly distributed. Visits for patients with Phenylketonuria and cancer were the most common. (See Tables 19-20)

Table 19. Distribution of type of visit for Oregon telehealth visits

Visit Type	No.	%
Genetic condition other than metabolic	31	48.44%
Metabolic genetic condition	31	48.44%
Newborn screening metabolic condition	2	3.13%
Total	64	100.00%

Table 20. Distribution of diagnoses* in Oregon telehealth visits, 2005-2008

Diagnosis 1	No.	% of Visits
Phenylketonuria	13	20.31%
Cancer	10	15.63%
Unknown	8	12.50%
Ornithine transcarbamylase deficiency	4	6.25%
Biotinidase deficiency	2	3.13%
Medium-chain acyl-CoA dehydrogenase deficiency	2	3.13%
Gluteric aciduria type 1	2	3.13%
Albinism	1	1.56%
Autism spectrum disorder	1	1.56%
Autosome abnormality	1	1.56%
Breast cancer family history	1	1.56%
Carnitine palmitoyltransferase II	1	1.56%
Carnitine uptake deficiency	1	1.56%
Cavernous malformation	1	1.56%
Charcot-Marie-Tooth III	1	1.56%
Citrullinemia	1	1.56%
Cleft lip and palate	1	1.56%
Cornelia de Lange syndrome	1	1.56%
Down syndrome family history	1	1.56%
Dysmorphic cranial features	1	1.56%
Failure to thrive	1	1.56%
Fragile X syndrome	1	1.56%
Holt-Orum	1	1.56%
Hyperammonemia	1	1.56%
Isovaleric acidemia	1	1.56%
Left hemisphere hypertrophy	1	1.56%
Lesch-Nyhan syndrome	1	1.56%
Macrocephaly	1	1.56%
Methylmalonic acidemia	1	1.56%
Neurofibromatosis	1	1.56%
Noonan syndrome	1	1.56%
Tuberous sclerosis	1	1.56%
Wolf--Hirschorn syndrome	1	1.56%
Total=33 diagnoses (3 duplicated patients)	64	

* Some patients had more than one diagnosis

Oregon Family Satisfaction—Telehealth Visits

Tables 21-23 show the distribution of responses to the satisfaction survey completed by families participating in Oregon telehealth visits. Seventy-eight percent of respondents either disagreed or strongly disagreed with a statement that they would prefer to travel to see the specialist in person. Data is available from 32 respondents.

Table 21. Distribution of responses to Oregon telehealth visit family satisfaction survey

Patient Satisfaction	% Strongly Agree	% Agree	% Disagree	% Strongly Disagree	% NA	No.
The information I received <u>before the visit</u> helped me understand what was going to happen.	38.7	54.8	3.2		3.2	31
Staff could work the equipment.	66.7	33.3				12
The equipment worked well.		41.9	3.2	51.6	3.2	31
Before we started, each person introduced themselves and described their role.	61.3	33.3				30
The use of technology did not get in the way with being able to have a good conversation with the specialist.	61.3	38.7				31
The specialist listened and respected the information I provided.	74.2	25.8				31
The specialist responded to all of my questions.	77.4	22.6				31
Privacy of information about my child and my family was protected.	67.7	29			3.2	31
I feel confident in the quality of the care provided today.	71	29				31
I feel confident in the recommendations from today's visit.	67.7	32.3				31
I would recommend telehealth to other families.	79.3	20.7				29
Overall, I was satisfied with the visit today.	79.3	20.7				29
Despite the obstacles to receiving care in person, I would STILL prefer to travel to see the specialist.	3.6	17.9	42.9	35.7		28
Has telehealth made it any easier to get the care you need for your child?	96.4% Yes	3.6% No				28

Table 22. Distribution of responses to Oregon telehealth satisfaction survey—“Before today’s visit, what made it hard to get the specialty services your child needs?”

Family Satisfaction	No.=32	%
I miss work and/or lose wages		62.5
It costs too much to travel		59.4
It costs too much (insurance)		28.1
It is hard to get and/or pay for child care		18.8
Going to a large hospital is not comfortable		9.4

Table 23. Distribution of responses to Oregon telehealth satisfaction survey—“If you had not been able to use telehealth to get specialty care today, what would you have done?”

Family Satisfaction	No.=32	%
Would have traveled to Portland		56.3
Would have waited until specialist came near to my home in an outreach clinic		40
Would have seen local provider		18.8
Would have not gotten the care my child needed		12.5

Oregon Personnel Time

Personnel involved in the Oregon telehealth project estimated the amount of time spent for patients before, during and after the visit as show in Table 24 below. Personnel estimated their time for the number of patients shown in the center row of the table. Dividing the number of patients by the estimated time spent offers an estimated number of hours per patient for each type of personnel. Totaling these estimated average hours per patient across all types of personnel involved in a telehealth visit yields an estimated number of personnel hours for one telehealth visit.

Table 24. Estimated number of hours per patient visit by personnel type in the Oregon telehealth visit project

	GC	MG	DT	PAA	AA	MA	OF	ORT	OHSUT	Total Est.
No. hours*	18.50	21.75	19.75	27.50	1.75	0.25	3.43	1.83	4.67	
No. Patients	9	15	8	15	7	1	2	9	2	
Hrs/patient	2.06	1.45	2.47	1.83	0.25	0.25	1.71	0.20	2.33	12.56

*Total hours spent before, during and after seeing patients for the number of patients seen listed in row below.

GC-genetic counselor; MG-medical geneticist; DT-dietitian; PAA-assistant; AA-assistant; MA-medical assistant; OF-patient site facilitator; OHSUT-specialist site technician

WSGSC funded a portion of salary and travel costs for a medical geneticist and dietitian to travel to Lewiston, Idaho Falls and Coeur d’Alene, Idaho to provide outreach genetic consultation to patients with metabolic conditions. Time and cost data was not collected for these outreach trips. However, personnel estimated their time for trips to Boise and Eugene, Oregon. Totaling the estimated time before, during, after and traveling to the

patients, offers the following estimates for personnel time in sample Oregon outreach visits to Idaho. (Table 25)

Table 25. Estimated personnel hours per patient visit for Oregon outreach project

	Estimated No. of Hours	No. Patients	Estimated Hours/Patient
Medical geneticist	39.25	36	1.09
Dietitian	26	8	0.72
Medical assistant	27.5	28	0.76
Total estimated personnel hours for one outreach visit			2.58

Oregon Personnel Travel Cost

Cost data was not collected for the Oregon outreach projects funded by WSGSC. However, personnel reported travel costs for a sample outreach clinic to Boise Idaho where thirty-six patients were seen. The travel costs were estimated for a medical geneticist, dietitian and medical assistant to fly to Boise and spend one overnight. The estimated total cost for such a trip was \$1,439, which results in an estimate of \$39.98 travel cost per patient for sample outreach visits to patients in Boise with metabolic conditions.

Washington-Alaska Findings

The Washington project was funded primarily by the Washington State Department of Health Genetic Services Section with a Maternal Child Health Bureau grant ((Project #H91MC00219 from the Maternal and Child Health Bureau (Title V, Social Security Act) #1126, Health Resources and Services Administration, Department of Health and Human Services)). WSGSC contributed partial funding to years two and three of the Washington project for a pilot interactive telehealth conference project. The project was administered by the Medical Genetics Division at Seattle Children’s and evaluated by staff at Seattle Children’s Center for Children with Special Needs. Medical geneticists at Seattle Children’s provided consultation to patients referred by genetic counselors at the Central Washington Genetics Program, a Washington State Department of Health (DOH) funded Regional Genetics Clinic administered by Yakima Valley Memorial Hospital. Telehealth equipment was located at the Seattle campus, Children’s Village in Yakima, and an outreach clinic in Wenatchee. DOH funds the Regional Genetic Clinics (RGC) to assure access to specialty genetic services. As part of routine RGC activity, genetic counselors receive and triage referrals from community providers, determining whether referred patients might benefit from a medical genetics consultation. In the telehealth pilot, genetic counselors were to routinely review a list of patients awaiting a clinic visit from a CHRMC-based medical geneticist in order to identify patients who would be eligible for a telehealth visit. Criteria for whether a patient was eligible for a telehealth visit included: 1) needed visit was a follow-up visit; 2) minimal physical examination was deemed necessary; or 3) needed visit was an urgent initial visit. If a telehealth consultation could be scheduled prior to the next time the medical geneticist

would be in Yakima for an in-person clinic, the genetic counselor then offered the patient the opportunity to see the physician earlier via telehealth. At initial contact and at the time of the telehealth visit, genetic counselors gave the patient information about what to expect during the telehealth visit.

The WSGSC also contributed funds for a team of genetic specialists to travel to Anchorage, Fairbanks, Juneau, Ketchikan and Sitku to provide outreach clinics.

Washington Methods

Alaska public health genetic services and newborn screening program collected data on the location and number of patients who received outreach visits from the Seattle specialty team.

Qualitative information about the telehealth project process and visits and quantitative satisfaction data at each visit was collected. Genetic counselors and physicians supplied both verbal and written feedback to evaluation staff at team meetings. Questionnaires related to satisfaction with the telehealth visit were completed by a family member of pediatric patients or the adult patient themselves, interpreters present during the visit, referring providers, genetic counselors and medical geneticists. During the final year of the project, satisfaction questionnaires were also completed by a sample of patients receiving in-person medical genetic consultations at the Yakima clinic.

Genetic counselors and medical geneticists completed questionnaires immediately after each visit. During the three years of the project, three genetic counselors and two medical geneticists participated in patient visits. Genetic counselors were to use a prescribed protocol to offer patients and interpreters the opportunity to complete a satisfaction questionnaire immediately following their telehealth or in-person visit with the medical geneticist. Once the medical geneticist's consultation report was mailed to the referring provider, evaluation staff mailed a cover letter and satisfaction questionnaire to referring providers, asking them to complete and return the survey.

Information about cost and billing was obtained from Seattle Children's contract manager, Children's University Medical Group (the physician billing office for CHRMC), CHRMC Information Systems department, and YVMH finance office. All qualitative and quantitative data was collected, entered and analyzed by evaluation staff at the Center for Children with Special Needs. Tables 26-32 report on data from September 1, 2004 – April 30, 2007. Table 26 shows the number of visits provided in the outreach project.

A total of 37 visits were provided between 9/24/2004 and March 17, 2007 by three different genetic counselors and two medical geneticists. The average number of patients seen per day for which visits were scheduled was 1.5. Tables 26-32 show the distribution of patient characteristics for telehealth visits.

Table 26. Distribution of patient age in Washington telehealth visits

Patient age in years	No. of patients
<1	1
1	2
2	1
3	3
4	1
5	2
6	6
8	2
11	1
12	4
17	1
18	1
28	1
30	1
Total	27
Mean age for 0-21 YO's=7 years, SD=.98	

Table 27. Distribution of patient gender, ethnicity and visit type for Washington telehealth visits

Gender	No.	%	Ethnicity	No.	%	Type	No.	%
females	17	59%	Hispanic or Latino	16	53%	follow-up	32	86%
males	12	41%	Caucasian	12	40%	initial	5	14%
Total	29	100%	Mixed ethnicity	2	7%	Total	37	100%
			Total	30	100%			

Table 28. Diagnoses of patients receiving medical genetic consultation via interactive telehealth conference between Yakima and Seattle, September 1, 2004 - April 30, 2007

Diagnosis	No. of Visits
achondroplasia	1
arthrogryposis	1
Autism	1
Bannayan-Riley-Ruvalcaba syndrome	1
Beckwith-Wiedemann syndrome	1
brain malformation	1
carnitine palmitoyltransferase deficiency Type I	2
chromosome abnormality	1
developmental delay	6
duodenal atresia	1
Freeman Sheldon syndrome	1
glycogen storage disease	1
hypertelorism	1
Marfan syndrome	1
mosaic chromosome 10	1
mucopolysaccharidosis VI	1
neuromuscular unspecified	1
neurofibromatosis	2
Noonan syndrome	1
overgrowth	1
polydactylism	1
Russell-Silver syndrome	1
skeletal dysplasia	1
subcorticate band heterotopia	1
Turner syndrome	1
unknown	2
Von Hippel-Lindau syndrome	2
Wolf-Hirschhorn syndrome	1
Total	37
Total diagnoses	28

Washington Satisfaction—Telehealth Visits, Family and Provider

As shown in Table 29 families were equally satisfied with telehealth and in-person consultations. Families had the highest mean satisfaction for telehealth visits compared to interpreters and referring providers.

Table 29. Participant satisfaction* with medical genetics consults provided via interactive telehealth conferencing from Seattle Children's Hospital to Central Washington Genetics Program, 2004-2007

*Overall satisfaction, based upon responses to post-visit satisfaction questionnaire

5=strongly agree - 1=strongly disagree	Mean of means from all satisfaction questions	No. of participants	No. visits
families – telehealth visits	4.90	29	29
families – in-person visit	4.81	28	28
interpreters	4.87	11	11
referring providers	4.36	19	19
genetic counselors	4.73	3	37
medical geneticists	4.45	2	23

Table 30 shows that most of the respondents who completed post-visit satisfaction surveys were mothers of pediatric patients for whom the visit was scheduled. Two adult patients completed satisfaction surveys after telehealth visits.

Table 30. Respondent relation to patient among Washington family satisfaction surveys

*Respondent relation to patient-telehealth visits	No.
mother	26
father	7
grandmother	2
self	2
** Respondent relation to patient-in person visits	No.
mother	8
father	2
both parents	2
grandmother	2
self	2

Washington—Telehealth Visits Insurance Billing and Reimbursement

Medical genetic consultations were billed from Seattle Children's. Third party reimbursement for consultations varies based upon individual insurance plan. Insurers

reimbursed for telehealth at the same rate as in-person visits, according to Children's University Medical Group billing office. The rate of reimbursement ranges from 25-96%.

Table 31. Percent of charges covered by insurance for medical genetic consultations provided via telehealth conferencing from Seattle Children's to Central Washington Genetics Program, September 2004-March 2007

ICD9	CPT Code	CPT Code Description	Hours Billed*	Insurance or Plan Name	Insurance Covered Y/N	% Insurance Covered	Charges
759.89	99215 GT	Off OtPt Vst	40 + minutes	DSHS	Y	35%	\$239.25
271	99215 GT	Off OtPt Vst	40 + minutes	DSHS	Y	35%	\$239.25
758.6	99244	Office Consult	60 minutes	FC Cigna	Y	41%	\$342.75
759.7	99245 GT	Office Consult	80 minutes	CHPW	Y	25%	\$442.50
759.89	99215 GT	Off OtPt Vst	40 + minutes	DSHS	Y	35%	\$239.25
243	99215 GT	Off OtPt Vst	40 + minutes	Molina WVC	Y	35%	\$139.25
759.7	99245 GT	Office Consult	80 minutes	Molina	Y	26%	\$442.50
742.4	99215 GT	Off OtPt Vst	40 + minutes	Premera/Regence	Y	96%	\$239.25
315.2	99215 GT	Off OtPt Vst	40 + minutes	DSHS	Y	Refunded/ 0	\$237.75
330.8	99245 GT	Office Consult	80 minutes	Regence	Y	68%	\$442.50
780.39	99215 GT	Off OtPt Vst	40 + minutes	DSHS	Y	35%	\$237.75
756.4	99215 GT	Off OtPt Vst	40 + minutes	none		write off	\$237.75
312.9	99215 GT	Off OtPt Vst	40 + minutes	DSHS	Y	36%	\$237.75
758.5	99215 GT	Off OtPt Vst	40 + minutes	DSHS	Y	36%	\$237.75
758.39	99245 GT	Office Consult	80 minutes	DSHS	Y	25%	\$442.50
756.4	99244 GT	Office Consult	60 minutes	Premera	N		\$342.00
755.5	99215 GT	Off OtPt Vst	40 + minutes	CHPW	Y	36%	\$237.75
277.5	99911 C	No Charge	unknown	none			\$0.00
754.89	99911 C	No Charge	unknown	DSHS			\$0.00
780.39	99215 GT	Off OtPt Vst	40 + minutes	DSHS	Y	36%	\$237.75
759.82	99911 C	No Charge	unknown	Regence HO			\$0.00
781.3	99215 GT	Off OtPt Vst	40 + minutes	DSHS	Y	37%	\$237.75
783.42	99215 GT	Off OtPt Vst	40 + minutes	DSHS	y	37%	\$237.75
759.7	99215 GT	Off OtPt Vst	40 + minutes	DSHS	Y	37%	\$237.75
237.71	99215 GT	Off OtPt Vst	40 + minutes	Health Comp	Y	54%	\$237.75
756	99215 GT	Off OtPt Vst	40 + minutes	DSHS	y	37%	\$237.75
759.7	99215 GT	Off OtPt Vst	40 + minutes	DSHS	y	34%	\$256.50

Source: CUMG Office, Children's Hospital and University Hospital Medical Group Billing used time in CPT Book

Genetic counseling services provided during telehealth conferencing at Central Washington Genetics Program were not a billable service because the counselor and physician saw the patient at the same time. Also, Yakima Valley Memorial Hospital's contract with Medicaid and other insurer's precludes billing for telehealth. (Source: Kathy Pratt, Charge Description Master Specialist, Yakima Valley Memorial Hospital)

Washington to Alaska Outreach

A total of 630 genetic specialty outreach visits were provided to Alaskan residents between 2006 and 2008 with partial funding from the WSGSC.

Table 32. Number of outreach visits provided by Washington genetic specialists in Alaskan towns by town and year

Alaskan Town	No. Visits 2006-2007	No. Visits 2007-2008
Anchorage	197	232
Bethel	5	1
Fairbanks	58	76
Juneau	24	21
Ketchikan	7	5
Sitku		4
Total	291	339

Across the Practice Model—Number and Type of Visits

Eighty-four percent of all visits in the Practice Model were outreach visits while 16% were telehealth visits. Table 33 shows the number of outreach visits, by state and grant period, received by people living far from genetic specialists. Data regarding duplicate patients is not available. Thirty-nine percent of outreach visits were provided by a Seattle genetics team who traveled to patients in Alaska while 47% of outreach visits were provided by a Honolulu genetics team who traveled to patients in Guam and other Hawaiian islands. Outreach to Guam was suspended after project staff determined working for health insurance reimbursement for genetic testing was necessary in that territory before continuing outreach clinics. Excluding Guam, the number of outreach visits has increased each year.

Table 33. Number of outreach visits in the Practice Model by state in which services were provided and grant year

Grant Year	Alaska	Guam	Hawaii	Idaho	Total
2005-2006			30		30
2006-2007	95	25	94	33	247
2007-2008	108		95	41	244
Total	203	25	219	74	521

Table 34 shows the number of telehealth visits received by western families living far from genetic specialists. All counts reflect unduplicated patients with the exception of Oregon where there are 54 unduplicated patients receiving 59 visits. Of the 96 genetic consultations provided via telehealth conferencing between 2005 and 2008, 61% were in Oregon. Washington State discontinued telehealth visits after a three-year trial project. WSGSC provided no funding for the first year of the Washington project.

Table 34. Number of telehealth visits in the Practice Model by state for which services were provided and grant year

Grant Year	Hawaii	Idaho	Oregon	Washington	Total
2005-2006		3	4	10	17
2006-2007	8	1	20	10	39
2007-2008	4	1	35		40
Total	12	5	59	20	96

Across the Practice Model—Visit and Patient Characteristics

Visit and patient characteristic data was collected for Hawaii outreach visits and Oregon and Washington telehealth visits. Table 35 shows similarities and differences with regard to type of visit and age of patients seen in these two programs.

Table 35. Distribution of visit and patient characteristics in Hawaii outreach and Oregon and Washington telehealth visits

Characteristic	Hawaii Outreach Visits No.=80	Oregon Telehealth Visits No.=64	Washington Telehealth Visits No.=37
Initial visit	51%	68%	14%
Follow-up visit	49%	32%	86%
Metabolic diagnosis		48%	8%
<12 months old	8%	25%	4%
12-35 months old	30%	20%	11%
3-13 years old	46%	23%	70%
14-20 years old	11%	8%	7%
>= 21 years old	5%	23%	7%

Qualitative Findings

Project staff and clinicians report the following challenges to each type of service delivery model:

Challenges Present in Both Outreach and Telehealth Visit Models

- Specialists might not have time to add travel to existing case load
- Specialists might not have time to add new patients to existing case load
- In some instances, if medical geneticist and genetic counselor are together with patient, genetic counselor can not bill patient

Challenges to Outreach Delivery Model

- Higher number of specialist personnel hours due to travel, varies based upon travel distance, time and costs
- Personnel travel time and costs not reimbursed by insurance

Challenges to Interactive Telehealth Conferencing Model

- Non-billable professional time to identify and triage patients
- Some physical examinations must be doctor hands-on
- Some patient populations elect in-person
- Provider willingness to participate necessary
- Intra and inter-organization systems slow to change procedures
- Adds layer of complication onto existing service types
- Partnership or inter-agency agreements must be created and maintained
- Increased non-billable coordination and management time to maintain all program aspects, including quality
- Technical or equipment aspects still not perfect
- Professional with patient might not be able to bill (duplicate billing)

Discussion and Conclusions

Findings from the Practice Model evaluation can assist public health agencies and tertiary centers in planning access projects, but the following factors should be considered:

1. There were more differences in genetic specialists time between states than between service delivery models
2. Salary differences between same types of specialists
3. Travel time differences between outreach clinic locations
4. Costs of travel changed over time
5. Differences in genetic specialists time for initial vs follow-up visits
6. Costs for connectivity between each set of sites (T1 line, ISDN line, Internet)
7. Used a formative evaluation strategy so processes changed over time
8. Whether numbers of families seen actually increased or the service delivery model simply changed
9. Varying combinations of genetic specialists

To serve families living “far away” from a genetics center, adding outreach or telehealth programs reduces costs for families and adds costs to the health care delivery system.

Recommendations specific to telehealth projects:

- Success more likely with a physician geneticist “champion”
- Visit indications that worked the best
 - Metabolic management for known patients
 - Follow-up medical geneticist consultation
 - Pre and post test genetic counseling for adult-onset conditions
 - Genetic counseling when a physical exam is not needed
- Add logistics responsibilities to existing clinic administrative/support staff rather than hiring a separate coordinator for telehealth
- Make the telehealth equipment as accessible as possible for the genetics specialists
- Schedule telehealth visits as “clinics” - as many patients at one originating site on the same day
- Add genetics to an existing telehealth system if one exists