

# Quarterly Report

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## National Network of Libraries of Medicine - MidContinental Region Region 4

May 1, 2008 - July 31, 2008

Contract No. N01-LM-6-3504

Spencer S. Eccles Health Sciences Library  
University of Utah

Submitted January 14, 2009

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# Executive Summary

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## Personnel

Jean Shipman accepted the position as Director of the RML and the Spencer S. Eccles Health Sciences Library. Her start date is October 1, 2008.

Orientation for Jim Honour, Wyoming Liaison, proceeded throughout the quarter.

Sandy Drollinger was hired as Financial Analyst. Her start date is August 4, 2008.

The final report on sharing the Technology Coordinator position was submitted to NLM. (See Attachment 3)

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## Advocacy

Barb Jones, Missouri/Library Advocacy Liaison, completed follow-up interviews with participants in the MCMLA Library Advocacy Task Force Survey. She gathered more data on the services the libraries provide to administrators; the existence of a marketing plan; and whether budget and staffing had gone up, down or remained level.

Ms. Jones has started recruiting hospital librarians in Missouri and Colorado for the value of librarians/libraries research study. This is a research effort being led by the J. Otto Lottes Library. A core set of questions is asked by every participating library so comparisons can

be made. The additional benefit to participation is that librarians can add questions to customize the questionnaire to their local environment.

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## Community Outreach

Rebecca Brown, Kansas/Technology Liaison, contributed health information items to the US Department of Health and Human Services Region VII Office of Minority Health Weekly Update.

Siobhan Champ-Blackwell, Community Outreach Liaison; Claire Hamasu, Associate Director; and John Bramble, Utah/Network Membership Liaison; as members of the TC4C Effective Practices work group, reviewed the proposals submitted for TC4C community partnerships. They approved the Arizona project and developed questions for the projects submitted by Utah and New Mexico for areas that were unclear.

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## Consumer Health

Ms. Champ-Blackwell and Dana Abbey, Colorado/Consumer Health Liaison, attended the American Library Association Annual Conference. Ms. Champ-Blackwell was very involved in wellness activities developed for the conference. She helped run the Wellness Fair that attracted about 500 people and spoke in the Membership Pavilion about ALA's Wellness Initiative. Both Ms. Abbey and Ms. Champ-Blackwell were presenters during the main

conference program and Ms. Champ-Blackwell was on a health disparities panel.

Ms. Brown established a Kansas consumer health wiki based on the comments of the Kansas public library focus group held in April. It started with five subscribers and is now up to seventeen.

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## Education

Marty Magee, Nebraska/Education Liaison, weeded and selected new technology and management titles for the NetLibrary collection.

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## Network Membership

In preparation for the RML Directors meeting at MLA, data was collected from the region. Resource Libraries were asked to respond to questions on their transition to electronic collections. All but two Resource Libraries responded to the questions. Resource Library Directors, Regional Advisory Board members, and Eccles Library faculty were invited to respond to questions about trends and the impact of those trends on the NN/LM program for 2011-2016. One director and two advisory board members contributed to the response from the MCR. Both reports were submitted for the minutes of the RML Directors' meeting.

### Regional Licensing Consortium

The Regional Licensing Consortium Advisory Group prepared the 2008-2009 fiscal year offering of electronic resources. Resources from the Future Science Group, Sage Publications, EBSCOHost, and Elsevier will be negotiated for the region. Renewal negotiations were started for ACP Pier.

The Pacific Southwest Region decided to initiate a collaboration with a licensing group in California and will not be participating in the

consortium with BCR. Under a new CEO, BCR continues to clarify with the RML expectations of its role in negotiating license agreements for the region. Ms. Hamasu and Mr. Bramble held a meeting with Brenda Bailey-Hainer, President and CEO for BCR. BCR expected increased revenue with additional RMLs and increased MCR member participation. Under the agreement between BCR and the RML, BCR feels that it is not being financially compensated for the work that is required to make electronic resources available to MCR members. BCR and MCR will continue negotiations.

### Reference Continuity Service

In July, the first two libraries were matched through the Reference Continuity Service Project: the medical libraries of the Poudre Valley Health System in Colorado and Campbell County Memorial Hospital in Wyoming. Mr. Bramble facilitated the agreement between the librarians on their backup service points. They decided to work under an informal, unsigned agreement.

### Emergency Preparedness

Ms. Brown is one of a three-person committee to create an emergency preparedness plan for the Dykes Library. The final output is a continuity of operations plan.

All staff participated in the day long event planned by Dan Wilson, coordinator for the NN/LM National Emergency Preparedness Plan, and Susan Yowell, project assistant. Staff agreed to carry out the following activities:

- spread the word through consortia in the region as well as the state organizations
- publish a briefing about the plan and the services available
- encourage applications for awards to fund implementing the plan
- address the MLA chapter meeting about the plan
- host a Moodle class

- include information about the plan in personal site visits
- offer something (e.g., dPlan, etc.) that members can start at the meetings
- create promotional materials for the plan (e.g., a brochure) for use within the region
- create promotional materials for the Toolkit site (e.g., baseball cards) to hand out at meetings, etc.

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## Technology

The Health Sciences Library at the University of Colorado Denver joined other Resource Libraries in PIG testing this quarter. There was a successful event on June 18, 2008, when Dan Wilson's presentation on emergency planning was broadcast from the Eccles Health Sciences Library to Resource Libraries in Colorado, Nebraska, Kansas, and Missouri (Washington University). Other libraries did not have their PIGs set up and heard the presentation via teleconference.

Ms. Brown organized the first informal meeting of the Technology Coordinators to discuss current projects, collaboration opportunities, and generally assist each other. This serves a different purpose from the sessions organized by Web-STOC.

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# Network Infrastructure

Table 1: Quarterly Infrastructure Data

	Current quarter	Previous quarter
Network members – full	166	168
Network members – affiliate	150	146
Libraries providing services to unaffiliated health professionals	102 (61%)	105 (63%)
Libraries providing services to public users	111 (67%)	115 (69%)
Average fill rate for resource libraries	76%	78%

- Closed: Lutheran Community Hospital, NE
- Full to Affiliate Membership: St. John's Medical Center, WY
- New Affiliate Members:
  - o University of Saint Mary, KS
  - o Topeka and Shawnee County Public Library, KS
  - o Utah College of Dental Hygiene, UT

Ms. Jones learned that the library at St. Joseph Hospital in Kirkwood, Missouri is being asked to eliminate all its holdings. This is part of the reorganization of the Sisters of St. Mary's Hospital system. All system hospitals in the St. Louis area will fall under one of two managers. Several of the hospitals are expanding into new facilities, and there is a potential for growth of library services throughout the system.

Ms. Jones presented a proposal at the July DOCLINE Coordinators' meeting to collect data on closed libraries throughout the country. Pat Devine, Network Coordinator from the Pacific Northwest Region, and Mr. Bramble will work with her on this effort.

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## Regional Advisory Board Activities

Ms. Hamasu gathered suggestions for new board members from the liaisons and composed a Regional Advisory Board representative of the diversity in the region. All candidates accepted their invitations to serve on the board, and letters confirming their appointments were mailed in July. An orientation session for board members, conducted by Joan Stoddart, Acting Director, and Ms. Hamasu, is being scheduled.

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## Needs Assessment and Evaluation Activities/Data

Betsy Kelly, Assessment and Evaluation Liaison, and Ms. Jones finalized the Cost Benefit Analysis/Return on Investment calculator and promoted it on the MCR web site. (<http://nmlm.gov/mcr/evaluation/roi.html>)

Ms. Kelly and Mr. Bramble emailed a draft of the Network Member Questionnaire to testers from the Regional Advisory Board. The questionnaire collects information about the resources and services available from our health sciences library members.

Usability tests for the MCR web site were conducted by AIR from May 7-15, 2008. Ms. Brown and Sharon Dennis, Technology Coordinator, reviewed the recordings. They gleaned additional action items from the viewings to add to the recommendations of the final report.

On July 11, 2008, Ms. Hamasu participated in an orientation for site visit team members to the New England Region (NER) held by Angela Ruffin. Others on the team are Harold Schoolman (chair), Holly Buchanan (University of New Mexico), and Michelle Brewer (New Jersey Hospital Association). NER's proposal, newsletters, and reports were reviewed in preparation for the visit. The site visit took place on Thursday, July 24, 2008. It was very well organized, and Ms. Hamasu got ideas on how to structure the MCR site visit and adapt the NER advocacy program for this region. She drafted her report as a team member addressing the strengths of the NER, challenges and recommendations for the NER, recommendations for NLM, and other comments.

A Network member from Missouri reported that DOCLINE did not have the current records for a journal title change. This was reported to NLM who appreciated being told of the problem and fixed it.

# Outreach

Table 2: Newly Funded Awards and Projects

Start/ end dates	Title of award/ project	PI institution	PI last name	Funding amount	Project type
	No new projects				

In year 2, the RML administered a questionnaire about our funding efforts. Participants could indicate whether they wanted liaisons to contact them. Ms. Jones and Ms. Magee followed up with Missouri and Nebraska members.

Ms. Champ-Blackwell consulted with the Nebraska AIDS Project, the University of Nebraska Medical Center (UNMC) Center for Health Disparities, and the UNMC McGoogan Library of Medicine on their proposal for the

NLM HIV/AIDS Outreach RFP. They were not able to meet the proposal deadline. She also advised the Cardiac Center of Creighton University about funding agencies and opportunities.

The RML forwarded three proposal summaries in response to the NICHSR funding for public health projects. Two were from Kansas and one was from Nebraska. None were funded.

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## Update of Ongoing, Major Projects

No Activity

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Table 3: Exhibits

Dates	Organization name	Meeting name	Location (city, state)
<b>RML NATIONAL EXHIBITS</b>			
6/9-12/2008	USPHS	Scientific and Training Symposium	Tucson, AZ
6/29-7/1/2008	National AHEC	NAO 2008 Conference	Denver, CO
<b>RML REGIONAL/STATE/LOCAL EXHIBITS</b>			
5/7/2008	St. John's Medical Center	Teton County Health Fair	Jackson, WY
5/13/2008	CIMRO of Nebraska	Nebraska Healthcare Quality Forum	Lincoln, NE
5/28/2008	Creighton University	AgeWell Senior Center Health Fair	Omaha, NE
6/18/2008	Omaha Public Library, Washington Branch	June Family Fair	Omaha, NE
6/19-20/2008	Colorado Rural Health Center	Colorado Rural Health Conference	Copper Mountain, CO

**Actionable Feedback received from Exhibit Visitors**

No suggestions or recommendations were received from exhibit visitors this quarter.

**MedlinePlus Go Local**

The Utah/TC4C Go Local coordinator moved to another state. Mr. Bramble assisted the library to complete its portion of the TC4C questionnaire. Discussion is being held within the library about Go Local responsibilities.

Table 4: Presentations and Training provided by RML Staff

Date	Last name of staff responsible	Title of presentation/training	Location (city, state)	Number of participants	In-person or distance education
5/2/2008	Bramble	Quality Health Information for School Nurses	Ogden, UT	16	In-person
5/7/2008	Bramble	Quality Consumer Health Information	Jackson, WY	6	In-person

<b>Date</b>	<b>Last name of staff responsible</b>	<b>Title of presentation/training</b>	<b>Location (city, state)</b>	<b>Number of participants</b>	<b>In-person or distance education</b>
5/9/2008	Magee	Health Resources for Diverse Populations	Bellevue, NE	7	In-person
5/13/2008	Bramble, Salmond	DOCLINE Routing Tables	Salt Lake City, UT	Synchronous 8	Distance Education
5/17/2008	Abbey, Champ-Blackwell, Sahali (PNR)	Getting Started with Information Outreach in Minority Communities	Chicago, IL	11	In-person
5/18/2008	Dennis, Sandstrom (PSR)	High Tech High Touch: Sharing Staff at a Distance	Chicago, IL	80	In-person
5/19/2008	Hamasu, Kelly	Demonstrating Effectiveness: One RML's Story	Chicago, IL	80	In-person
5/20/2008	Jones, Kelly	ROI Calculator	Chicago, IL	80	In-person
5/21/2008	Dennis	Blogs and Wikis	Chicago, IL	14	In-person
5/27/2008	Bramble, Salmond	DOCLINE for Beginners	Salt Lake City, UT	Synchronous 1	Distance Education
5/29/2008	Brown	Social Bookmarking: Bookmarking for the Greater Good	Kansas City, KS	Synchronous 14	Distance Education
6/5/2008	Salmond	DOCLINE Routing Tables	Salt Lake City, UT	Synchronous 4	Distance Education
6/11/2008	Champ-Blackwell	National Library of Medicine Resources for Minority Summer Research Interns	Omaha, NE	2	In-person
6/12/2008	Jones, Kelly	Measuring Your Impact	Traverse City, MI	21	In-person
6/13/2008	Magee	Thinking Like an MBA	Wilson, NC	22	In-person
6/18/2008	Brown, Dennis	Breezing Along with the RML	Kansas City, KS Salt Lake City, UT	Synchronous 42 Asynchronous 72	Distance Education
6/26/2008	Brown	Spanish Language Online Resources - Reaching Out to Spanish Speaking Communities	Kansas City, KS	Synchronous 6	Distance Education
6/30/2008	Champ-Blackwell	The Healthy Librarian: Cultivating Wellness in the Workplace	Anaheim, CA	78	In-person
6/30/2008	Champ-Blackwell	Partnering to Help Reduce Health Disparities in our Communities	Anaheim, CA	17	In-person
6/30/2008	Abbey	Take Two Aspirin: Helping Librarians Meet the Public Demand for Consumer Health Information	Anaheim, CA	43	In-person
July 2008	Magee	Thinking Like an MBA	Omaha, NE	5	Distance Education

<b>Date</b>	<b>Last name of staff responsible</b>	<b>Title of presentation/training</b>	<b>Location (city, state)</b>	<b>Number of participants</b>	<b>In-person or distance education</b>
7/8/2008	Dennis, Anderson (GMR)	Unwrapping New Technologies	Elkhart Lake, WI	40	In-person
7/10/2008	Dennis, Anderson (GMR)	Twitter	Salt Lake City, UT	15	Distance Education
7/11/2008	Abbey	NIH Public Access Policy and New Roles for Libraries in the Open Access Arena	Denver, CO	34	In-person
7/14/2008	Magee	Health Resources from the National Library of Medicine and more!	Norfolk, NE	9	In-person
7/15/2008	Champ-Blackwell	Research Resources from the National Library of Medicine for Minority High School Summer Students	Omaha, NE	45	In-person
7/16/2008	Abbey, Honour	Breezing Along with the RML	Denver, CO Laramie, WY	Synchronous 30 Asynchronous 51	Distance Education
7/17/2008	Brown	National Library of Medicine Consumer Health Resources	Iola, KS	14	In-person
7/17/2008	Magee	Health Resources from the National Library of Medicine and more!	Chadron, NE	9	In-person
7/19/2008	Abbey	Public Health Information Resources	Ft. Collins, CO	7	In-person
7/19/2008	Abbey	NLM Consumer Health Resources	Red Feather Lakes, CO	4	In-person
7/23/2008	Jones	Snake Oil to Penicillin	St. Louis, MO	13	In-person

## Other Staff Activities

Table 5: Publications and Resources Developed by RML Staff

Date completed/ published	Last name of staff responsible	Title	Medium	Submitted to Clearinghouse ("yes" or "out of scope")
May 2008	Champ-Blackwell	Consumer Health Information in Many Languages Resource update	Web site	Out of Scope
5/13/2008	Abbey	Clinical Inquiries: Patient Education 'Worrying About Memory Loss' (Editor)	Tear sheet– Evidence-Based Practice newsletter	Out of Scope
6/2/2008	Magee	Health Information on the Internet	Brochure	No
6/5/2008	Bramble	DOCLINE Classes update	Web site	Out of Scope
6/10/2008	Abbey	Clinical Inquiries: Patient Education 'Shin Splint Injuries' (Editor)	Tear sheet – Evidence-Based Practice newsletter	Out of Scope
6/26/2008	Dennis	Materials for Loan update	Web site	Out of Scope
7/15/2008	Abbey	Clinical Inquiries: Patient Education 'Arthritis and Exercise' (Editor)	Tear sheet– Evidence-Based Practice newsletter	Out of Scope
7/22/2008	Abbey	Standardized modules for MedlinePlus, Genetic Home Reference, NIH Senior Health, Household Products Database, ClinicalTrials.gov, and National Center for Complementary and Alternative Medicine	PowerPoint	No
7/27/2008	Champ-Blackwell	Update Native American, Asian American, African American, and Latino American health pages and the state Spanish pages	Web site	Out of Scope

One of our Missouri members sent an appreciative email to Ms. Brown. "I really enjoyed and profited from your Plains to Peaks [*sic*] article on social bookmarking, Rebecca. It was so clearly written and the imbedded links so apt that I really 'got it'."

The MCMLA- listserv had 357 subscribers at the end of the quarter.

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## Notable Staff Activities

*May 7, 2008*

Ms. Champ-Blackwell attended the board meeting for the Center for Human Diversity, a community-based organization.

*May 9, 2008*

Ms. Abbey attended the webcast “Tools of Engagement: Attracting and Engaging Library Users,” sponsored by BCR.

Ms. Hamasu added the description of the TC4C Public Library Project to the Outreach Connections: Native Health Information wiki.

*May 16, 2008*

All RML librarians attended the RML Directors’ meeting in Chicago and participated in the break out sessions.

*May 17, 2008*

Ms. Brown and Ms. Dennis attended the NN/LM Web-Dev meeting before MLA.

*May 27, 2008*

Mr. Honour emailed all Network members in Wyoming, introducing himself, providing his contact information, and inviting them to contact him.

*May 28, 2008*

Eduardo Crespi of Centro Latino invited Ms. Jones to participate in a meeting with other community and government organizations to explore ways that Centro Latino could collaborate and qualify for larger grants.

Ms. Abbey attended a planning meeting of the Culture of Data conference.

*May 30, 2008*

Ms. Brown attended a REFORMA meeting where she learned of BiNational Health Week activities planned for Kansas.

*June 4, 2008*

Ms. Hamasu, Ms. Dennis, and Mr. Bramble participated in the Eccles Health Sciences Library strategic planning retreat to look at the work that faculty is carrying out in relationship to the mission, values, and vision of the library and university.

*June 6, 2008*

Ms. Abbey attended “Taking Neighborhood Health to Heart: Partners for Health Project” a collaboration that includes the University of Colorado at Denver and Health Sciences Center to learn more about and improve the health of the neighboring communities.

Ms. Abbey attended the “Foundation of Cultural Dimensions” workshop to better understand what it is like to be part of a minority group. The workshop was sponsored by the university Office of Diversity and the Colorado Health Outcomes

*June 9, 2008*

Ms. Champ-Blackwell and Ms. Magee attended the Future Search Conference for librarians and city administrators, sponsored by the Nebraska Library Commission. They looked at trends for libraries and literacy.

*June 26, 2008*

Ms. Magee and Ms. Champ-Blackwell attended a web conference “Addressing Health Literacy” featuring Dr. Paul Smith, a physician from Wisconsin. The web conference was sponsored by CIMRO of Nebraska.

*July 2, 2008*

Ms. Champ-Blackwell attended the quarterly meeting of the Nebraska Minority Public Health Association.

*July 10, 2008*

Mr. Honour visited Affiliate member, University of Wyoming Institute for Disabilities Library. He was given a tour that included an overview of resources and description of the population that the library serves.

*July 10, 2008*

Mr. Honour attended training on Dreamweaver.

*July 18, 2008*

Ms. Magee presided over the State Advisory Council on Libraries meeting where she distributed materials on NLM and NN/LM resources.

*July 22, 2008*

Ms. Champ-Blackwell attended the meeting of the Nebraska C.A.R.E.S Omaha Cancer Health Disparities and recommended that they partner with McGoogan Library of Medicine and incorporate Go Local and the Consumer Health Information Resource Service into the resources they promote.

*July 24, 2008*

Mr. Honour visited Lesley Boughton, Wyoming State Librarian, and the State Library's outreach librarian. They discussed opportunities for collaboration.

*July 25, 2008*

Ms. Brown attended the Latino Health Issues Conference sponsored by the Kansas City, Missouri Health Department.

*July 28-29, 2008*

Mr. Honour visited libraries at the Wyoming Medical Center, Campbell County Memorial Hospital, Gillette VA Medical Center, University of Wyoming Family Medicine Residency Program, University of Wyoming Family Medicine Program, and Sheridan College.

*July 29, 2008*

Ms. Jones attended the ALA webinar "Congress: Coming Soon to a Community near You!"

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## Photographs



Dan Wilson presenting on emergency planning - June 18, 2008

# Attachments



# Attachment 1: Quarterly OARF Summary Data - RML Staff Activities

## Outreach Activities Conducted by MCR RML Staff

RML Q1, 2008-2009

Generated: Wednesday, October 15, 2008

22 Total Outreach Activities

*The following information is based on outreach reports of training activities.*

### Activities Summary

Total number of estimated participants:	441 participants
Average number of participants:	20.05 per activity
Average length:	1.72 hours
Under 1 hour:	2 activities (9.09%)
Between 1 and 2 hours:	16 activities (72.73%)
Over 2 hours:	4 activities (18.18%)
Hands-on practice:	12 activities (54.55%)
Conducted remotely:	4 activities (18.18%)
Offering continuing education:	2 activities (9.09%)
Significant number of minorities:	5 activities (22.73%)

### Session Content

PubMed:	10 activities (45.45%)
MedlinePlus:	15 activities (68.18%)
ClinicalTrials.gov:	3 activities (13.64%)
NCBI:	0 activities (0.00%)
NLM Gateway:	0 activities (0.00%)
TOXNET:	1 activity (4.55%)
Other technology content:	6 activities (27.27%)
Other, non-technology content:	7 activities (31.82%)

### Significant Minority Population Present

(>=50% of participants)

African American:	4 activities (18.18%)
Alaska Native:	0 activities (0.00%)
Asian and Pacific Islander:	1 activity (4.55%)
Hispanic:	1 activity (4.55%)
Native American:	0 activities (0.00%)

### Type(s) of Organization(s) Involved in Activities

Health sciences library:	22 activities (100.00%)
Public library:	2 activities (9.09%)
Government agency:	0 activities
Hospital:	1 activity (4.55%)
Clinical/Health care:	0 activities
Academic Institution:	22 activities (100.00%)
Community-Based:	2 activities (9.09%)
Faith-Based:	4 activities (18.18%)
Public Health Agency:	1 activity (4.55%)
Other:	5 activities (22.73%)

293 Participants Completed Participant Information Sheets

*The following information is based on Participant Information (PI) sheets collected during training activities.*

### Participants Summary

Activities at which PI sheet collected:	81.8%
Health care or service providers:	5 participants (1.71%)
Health science library staff members:	84 participants (28.67%)
Public Health worker:	7 participants (2.39%)
Public/Other library staff members:	160 participants (54.61%)
Members of general public:	37 participants (12.63%)



## Attachment 2: Promotional Materials Provided

<b>Date</b>	<b>Who</b>	<b>Items Provided</b>	<b>Purpose</b>
5/19/2008	Primary Children's Medical Center <i>Utah</i>	<ul style="list-style-type: none"> <li>- 1 MedlinePlus Poster</li> <li>- 2 Genetics Home Reference Card</li> <li>- 1 Tox Town Poster</li> <li>- 2 Connecting Native Americans To Health Information Card</li> <li>- 2 NLM Worlds Largest Medical Library Card</li> <li>- 2 Our Story Card</li> <li>- 20 PubMed Card</li> <li>- 20 DOCLINE Card</li> <li>- 2 Telemedicine Card</li> </ul>	Display as information for our patrons
5/28/2008	Rocky Mountain University of Health Professions <i>Utah</i>	<ul style="list-style-type: none"> <li>- 100 MedlinePlus Bookmark</li> <li>- 100 Haz-Map Occupational Health Database</li> </ul>	Information for advanced degree students during formal library instruction class
6/17/2008	Jackson Hole High School Media Center <i>Wyoming</i>	<ul style="list-style-type: none"> <li>- 150 MedlinePlus Bookmark</li> <li>- 2 MedlinePlus poster</li> <li>- 2 Consumer Health Card</li> <li>- 1 Consumer Guide to NIH HIV/AIDS Information Services Brochure</li> <li>- 3 Genetics Home Reference Card</li> <li>- 2 Tox Town Brochure</li> <li>- 1 Household Products Database Card</li> <li>- 1 NLM Worlds Largest Medical Library Card</li> <li>- 1 Our Story Card</li> </ul>	To assist in collaborative projects between the librarian and the health and biology teachers - Student research projects
7/31/2008	Longmont United Hospital <i>Colorado</i>	<ul style="list-style-type: none"> <li>- 50 MedlinePlus Bookmark</li> <li>- 50 MedlinePlus Bookmark (Spanish)</li> <li>- 100 NLM Pocket Card</li> <li>- 200 ClinicalTrials.gov Card</li> <li>- 200 Health Information for Senior Citizens Card</li> <li>- 10 Household Products Database Card</li> <li>- 50 NLM Worlds Largest Medical Library Card</li> <li>- 10 Our Collection/Our Databases Card</li> <li>- 100 PubMed Card</li> <li>- 50 NLM Gateway Card</li> <li>- 50 Public Health Resources</li> <li>- 50 WISER Card</li> <li>- 10 Specialized Information Services Card</li> <li>- 10 Telemedicine Card</li> <li>- 10 The Visible Humans Card</li> </ul>	handouts for: <ul style="list-style-type: none"> <li>-new employee orientation</li> <li>-cardiac rehabilitation groups</li> <li>-consumer handouts</li> <li>-nursing students</li> <li>-attachments with information packets</li> <li>-promotion of tax dollars in use for positive results</li> <li>-new physician tours/orientation</li> <li>-physician CME committee</li> <li>-cancer committee participants</li> <li>-public awareness/ library week</li> </ul>

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Attachment 3:  
Technology Position Sharing Final Report

**NATIONAL NETWORK OF LIBRARIES OF  
MEDICINE**

**MidContinental Region and Pacific Southwest Region  
Shared Position Evaluation  
Final Report  
July 1, 2007 to April 30, 2008**

**Sharon Dennis, Technology Coordinator  
Claire Hamasu, Associate Director  
Heidi Sandstrom, Associate Director**

**Submitted July 29, 2008**

**Shared Technology Coordinator Position  
National Network of Libraries of Medicine (NN/LM)  
MidContinental Region (MCR) and Pacific Southwest Region (PSR)  
Evaluation – July 1, 2007 to April 30, 2008**

The proposal for the Shared Technology Coordinator Position between the MidContinental Region (MCR) and Pacific Southwest Region (PSR) of the National Network of Libraries of Medicine (NN/LM) states the project will be deemed a success based on nine criteria. Each of these is addressed in this evaluation as follows:

1. Activities of the joint logic model (see Attachment 1) are completed.  
Activities were completed as planned for 6 of 11 PSR activities and 9 of 12 MCR activities as outlined in the joint logic model. There were problems implementing some of the activities and staffs are developing new strategies.

It should be noted that the quality of Sharon's work has been excellent in all activities; the level of activity far exceeded expectations in the areas of training and consultation with Network members and NN/LM PSR staff.

2. Indicators of the logic model are met. (see Attachment 2)  
Five of the eleven indicators were met as written. Progress was made on most of the indicators.
3. If either is not accomplished, there is an explanation which both Associate Directors find satisfactory.  
At least half of the measures of success have been met, according to the responses outlined in questions 1 and 2 (above). Some of the activities and indicators have not been completed within the scheduled time frame due to an ambitious schedule or to external reasons. The Associate Directors are very satisfied with the achievements of the technology logic model in both regions.
4. Staff members at both RMLs are satisfied with support from, and interaction with, the Technology Coordinator.  
PSR staff members are satisfied with the nature and quality of support from Sharon Dennis. Interactions have been perceived as very positive and supportive. The level of interaction has been less than expected, likely due to an "out of sight, out of mind" dynamic. Ways to increase the level of interaction have been proposed to PSR staff: adjusting settings on Skype so that it automatically opens on logon so Sharon knows who is available throughout the day; Sharon sending an email once a week to PSR staff as an inquiry and reminder of her availability to assist and consult on technology-related issues; Sharon spending more days at the Regional Network Office during her visits in order to increase opportunities for "face time" and casual interaction. Discussion with other RML Associate Directors are being held to learn how they integrated telecommuting staff into the communication patterns of the co-located staff.

MCR liaisons still receive excellent support from the Technology Coordinator. They have noticed that she is less available which reduces impulse contacts and favors contacting the Technology Liaison or someone else. The Technology Liaison, who works most closely with the Technology Coordinator, finds no change in Sharon's availability. They still have regularly scheduled meetings and her presence is noted on Skype whether she is in Salt Lake City or Los Angeles.

5. Each Region recognizes Sharon Dennis as the Technology Coordinator for the Region.

A questionnaire was sent to all MCR Network members in April 2008 asking for their perception of the service from the RML supporting the technology project area. We received 61 responses (not statistically significant but useful). The survey results assure us that Sharon Dennis continues to be recognized as part of the technology team.

[Note: The MCR has two librarians leading the technology project area—Sharon Dennis and Rebecca Brown. Some members may work with Rebecca Brown and may recognize her as the technology person in the MCR.]

Sharon has gotten a great response to the messages she has sent on the PSR electronic mailing list, her classes have filled immediately in response to invitations to register, and she has received calls from Network members following article publication in *Latitudes*. In lieu of surveying its Network members during the pilot period, PSR used feedback they provided on evaluations following Sharon's instructional sessions, and during individual consultations with her. We also received Network member feedback during our Resource Library Directors Meeting in October 2007, during the Joint MLA Chapters meeting in February 2008, and from our Technology Advisory Group, which met on May 9, 2008. In summary, when Sharon has announced classes in the region, she has consistently gotten a level of response that necessitates multiple offerings in the region. Class participants have indicated that they have acquired knowledge that they can apply to their work environments, and several have contacted Sharon afterwards to consult with her on specific technology issues/problems. Sharon's February 2008 Communications Questionnaire had a good response rate, and included comments such as the following, "Thanks to Sharon Dennis for the RSS, blog, Wiki classes." I have heard only positive comments about Sharon's extensive knowledge, skill and experience related to technology and her ability to translate technology-related content into understandable and actionable information.

6. In addition, the MCR members will be asked if they've noticed a change in level of service in our technology program.

A questionnaire was sent to all Network members in April 2008 asking for their perception of the service from the RML supporting the technology project area. We received 61 responses (not statistically significant but useful). The majority of the participants perceive that our service has either remained at the same level or increased.

7. If technology support staff were hired in the MCR, the Technology Coordinator and the technology support staff would jointly accomplish the logic model indicators and activities.

Technology Associate, Susan Roberts, started December 1, 2007 at .4 FTE. Sharon supervises this position. Susan is highly experienced in communication technologies and web design. Susan worked on a color redesign for the web site, assisted with the PIG / Access Grid set up and tests, wrote a manual for the Utah Access Grid operation, and

performed routine web site maintenance. She worked with several liaisons to assist them in creating or editing web pages and provided answers to web site questions as needed. In addition, she taught two distance education classes related to web site and image design using Adobe Connect; 24 members attended the classes.

8. The administrative overhead is not too burdensome as determined by the Associate Directors.

The administrative overhead has not exceeded that associated with any other coordinator position. Setting up the program required more coordination than was expected for a new project. Outlining the project and agreeing on policies and procedure was negotiated in a day-long meeting that included Heidi Sandstrom, Claire Hamasu, and Sharon Dennis. It took a reasonable amount of time to write the proposal. However, getting the subcontract through the approval processes of NLM, UCLA, and University of Utah took much longer than expected. Grants offices at all institutions involved are short staffed and overworked. Diligent follow up was required to verify that all necessary documents were provided and that the paperwork received priority handling and proceeded expeditiously. Whenever the ADs attention was required elsewhere progress slowed. After several months, NLM required that the start date originally established be changed from July 1 to August 14, 2007, requiring an amendment to the proposal. The subcontract required by UCLA was very formal and required involvement by more than the University of Utah's Office of Sponsored Projects before it could be approved and signed.

Because of the success of the pilot, both MCR and PSR agreed to extend the position-sharing arrangement for Year 03 of the contract, and to subsequently decide on a year-to-year basis to extend the arrangement for the remaining years of the contract. The extension has required only an amendment to the original subcontract agreement between the two RML institutions, a process that has been much simpler, involving minimal time and effort.

We anticipated being able to answer the following questions by conducting the pilot:

1. What is the best way to handle salary and benefits, as well as other costs associated with the position, between two NN/LM Regions?

Salary and benefits are administered through Eccles Health Sciences Library; the PSR portion is paid to MCR through the subcontract mechanism. Travel expenses are split evenly between MCR and PSR. Both provide office space, supplies, and equipment for the position. With salary as the only budget item in the subcontract both RMLs use their regular budgets for all other items providing them with flexibility in how they support the work of the position.

2. Can sharing be established with a "Handshake Agreement" among the RMLs involved?

Until the subcontract could be executed, sharing proceeded on a "good faith" agreement between the Associate Directors of MCR and PSR. However, since funds need to be exchanged between institutions, a "handshake agreement" would not work for a permanent arrangement. RMLs looking to share positions should consult with their grants office to determine the most simple way to execute an agreement for the shared position.

3. Can duties be shared or be fulfilled by one person for multiple regions?

The requirements of time and effort for the split MCR/PSR position have been met and seem reasonable based on the first 10 months.

4. Can support staff perform some of the duties currently being performed by professional staff?

Yes. Support staff have assisted the PSR Technology Coordinator for some time with the more routine activities associated with the position (e.g. equipment, web site maintenance, etc.)

Yes, a support position has taken over the responsibility of administrator for the listserv, promoting pages from the development to the public web site, teaching classes using Adobe Connect, and revising the web site.

5. How does administration of the regional program have to be modified to accommodate shared staff positions?

UCLA and the University of Utah required the subcontract funding mechanism for the shared position pilot, which required a bit more initial overhead of time and effort. Communication between the ADs must be consistent and clear relative to supervising and scheduling activities for this position. Cost savings must be reallocated within the program, while leaving open the possibility of terminating the shared position if circumstances in either MCR or PSR necessitate this.

6. What modifications need to occur in the operations of each RML to accommodate shared staff positions?

Each RML needs to ensure adequate access to IT software/hardware/files needed for the position in each region and feasible mechanisms for working remotely and communicating regularly.



Centralized staff needs to make an extra effort to be inclusive when the technology coordinator is working remotely. The online reporting system for the MCR was adapted to record and report out work done for the PSR.

For the RML sharing the position, responsibilities that could be allocated to a part time person and finding someone to take the position needed to happen in order to accomplish all that was planned for the technology project area.

7. What are the technology coordinator activities that done once serve both regions?  
Almost all, with the exception of one or two activities, fall under program elements not exclusive to either region. These include developing classes; researching and disseminating knowledge about new technologies. Sharon has done these activities once and applied them to both regions. The "Introduction to Blogs and Wikis" class is a good example. After updating the workshop in October for the MCR, she had only had to do a small update in December to offer it to the PSR. Projects that both RMLs see as beneficial such as testing and working with the NTCC to develop a national training web system and coordinating a web usability study for both regions also are carried out once.
8. Is the number of Network members related to the number of Network member contacts with the Technology Coordinator? PSR has more Network members than MCR. Does this result in more work for the Technology Coordinator?  
It is definitely true that any activity conducted for the PSR involving members results in an increased time commitment (for instance, offering more sessions of classes to meet demand, responding to more questions, etc.) However so far this has been manageable in the time allotted for PSR work.
9. How much in-person time is necessary for Sharon Dennis to be integrated into the NN/LM PSR staff?  
At least 2-3 days every other month seems optimal.
10. What are the major benefits and levels of satisfaction with the position-sharing arrangement— for the Regions, for the NN/LM staff (ADs, Technology Coordinator, other coordinators/liaisons), and for the institutions/RMLs (U of U Eccles Health Sciences Library, UCLA Louise Darling Biomedical Library)?  
The major benefits and levels of satisfaction are related to the unique qualifications and characteristics that Sharon Dennis brings to the shared position and to the collaboration between the regions that result from this arrangement. Feedback from PSR Network members has been very positive thus far. Not only is NN/LM PSR staff pleased with the arrangement, but UCLA Biomedical Library staff who work in the area of technology are as well.  
Sharing a position offers additional opportunities for staff without the individual having to leave a position and relocate. Sharon has enjoyed working with both regions. She enjoys teaching and consultations, so has appreciated the opportunity to expand these activities with the PSR members.  
Sharing a position with another RML has had no impact on the MCR project areas or on Eccles Health Sciences Library.

11. What are the major challenges of such an arrangement?

The major challenges are integrating this position into the UCLA Library organization, and the limited opportunity for “face time” with the technology coordinator. For the RML sharing the position, the challenge has been identifying the responsibilities that can be reallocated from professional staff to support staff in order that the technology project progresses as planned.

The success of the pilot has been driven to a significant degree by the individuals involved. Both Associate Directors have worked together before, on an intraregional level at PSR and on an interregional level between MCR and PSR on various other projects, so they are familiar with each other’s work and communication styles. In addition, Claire is familiar with the culture and characteristics of the region and UCLA, so is an additional resource to Sharon in this regard when questions arise.

Sharon Dennis not only brought her knowledge, expertise, and experience related to technology with her on Day 1 of the pilot, but also her knowledge of the NN/LM and its operations, and the relationships she has developed with NN/LM staff nationally. This has been of tremendous benefit to PSR; hiring an individual from outside of the NN/LM for the shared position would pose a significant orientation and training challenge for each of the regions.

As a staff member of two RMLs, discretion is required when she is involved in sensitive issues for either RML. Knowing what can and what should not be shared with the other RML librarians.

One of the big questions for PSR is whether .4 FTE is adequate for the needs of the region, which is larger in terms of Network membership than MCR, which has a combined total of 1.2 FTE (two .4 FTE professional and one .4 FTE) allocated for technology for that region.

The MCR now divides technology responsibilities among 3 people. It was a challenge for other staff to learn who to contact for a particular task and to remember each ones’ schedules. The MCR has resolved the issue by having staff send technology requests to all three. The 3 technology staff members have worked out a response procedure.

**Termination of the Pilot:**

The mid-year evaluation of the pilot coincides with the start (at the end of 2007) of the NN/LM annual budget renegotiation process. The evaluation indicates that the pilot has approached at least half of the measures of success, so the effort to share the Technology Coordinator position will be continued on a year to year subcontract.

**ATTACHMENT 1**

<b>NN/LM Goal</b>	<b>GOAL</b>	<b>OUTCOMES</b>	<b>INDICATOR</b>	<b>ACTIVITY</b>	<b>MCR: Notes</b>	<b>PSR: Notes</b>
Develop collaborations among network members and other organizations to improve access to and sharing of biomedical information resources throughout the nation	Assist NLM with the development and implementation of a plan to identify collections of historical and unique materials related to the health sciences	More historical and unique materials related to the health sciences will be identified and accessible to the public	There will be an increase in resources identified and added to NLM's "Directory of History of Medicine Collections" or another publicly accessible database	Follow NLM's lead to arrive at a practical definition of and scope for "historical and unique materials related to the health sciences"	No activity expected in Year 2.	No activity expected in Year 2.
Develop collaborations among network members and other organizations to improve access to and sharing of biomedical information resources throughout the nation	Assist NLM with the development and implementation of a plan to identify collections of historical and unique materials related to the health sciences	More historical and unique materials related to the health sciences will be identified and accessible to the public	There will be an increase in resources identified and added to NLM's "Directory of History of Medicine Collections" or another publicly accessible database	Collaborate with NLM and the other regions in the development of a national plan to identify these collections	No activity expected in Year 2.	No activity expected in Year 2.
Develop collaborations among network members and other organizations to improve access to and sharing of biomedical information resources throughout the nation	Enter into a formal agreement with at least one institution in each state in the region to serve as a Resource Library	Members adopt new technologies to increase access to biomedical information	Each resource library with a PIG is a participating site for at least one event using the PIG	The RML organizes Access Grid events and helps install PIGs at Resource Libraries	Year 1: 3 PIGs were installed at Creighton, UNMC, and Kansas. Year 2: install at Colorado, Wash. U, and Columbia. Coordinate events to be held in Year 2.	No activity expected in Year 2.

<b>NN/LM Goal</b>	<b>GOAL</b>	<b>OUTCOMES</b>	<b>INDICATOR</b>	<b>ACTIVITY</b>	<b>MCR: Notes</b>	<b>PSR: Notes</b>
Develop collaborations among network members and other organizations to improve access to and sharing of biomedical information resources throughout the nation	Establish and maintain channels for effective communication with current and potential NN/LM participants, other RMLs, NLM, and other state and multi-type library networks within the region	Increased collaborations and access to biomedical information via effective communication mechanisms	75% of members responding to surveys on periodic web surveys indicate increased knowledge of biomedical information due to reading the MCR's website	Develop and maintain a regional Web site as an integral component of the NN/LM Web site.	Routine web work to be handled by Rebecca. Continue to make improvements based on Year 1 usability study. Baseline survey to be conducted in late summer 2007; follow-up survey in April 2007. CMS implementation not likely in Year 2. Investigate other web technologies such as Google Gadget or other personalized options.	Involvement in routine web work to be determined according to PSR's needs. Continue to make improvements based on Year 1 usability study Baseline survey to be conducted in late summer 2007; follow-up survey in April 2008. CMS implementation not likely in Year 2. Investigate other web technologies such as Google Gadget or other personalized options.
Develop collaborations among network members and other organizations to improve access to and sharing of biomedical information resources throughout the nation	Establish and maintain channels for effective communication with current and potential NN/LM participants, other RMLs, NLM, and other state and multi-type library networks within the region	Increased collaborations and access to biomedical information via effective communication mechanisms	At least three video on demand events per year provided by the RML.	Participate in/testing/using other methods of communication, such as videoconferencing, computer conferencing, podcasts.	Offer on demand video via multiple delivery methods (this may include traditional streaming events, Flash streaming on demand videos on our server, or audio or video podcasts).	Offer on demand video via multiple delivery methods (this may include traditional streaming events, Flash streaming on demand videos on our server, or audio or video podcasts).  PSR anticipates creating 3 video events; members create 1 event.

<b>NN/LM Goal</b>	<b>GOAL</b>	<b>OUTCOMES</b>	<b>INDICATOR</b>	<b>ACTIVITY</b>	<b>MCR: Notes</b>	<b>PSR: Notes</b>
Develop collaborations among network members and other organizations to improve access to and sharing of biomedical information resources throughout the nation	Establish and maintain channels for effective communication with current and potential NN/LM participants, other RMLs, NLM, and other state and multi-type library networks within the region	Increased collaborations and access to biomedical information via effective communication mechanisms	At least one on-demand video provided by those trained.	Participate in/testing/using other methods of communication, such as videoconferencing, computer conferencing;	Training on how to create on-demand videos or podcasts offered to members, including those not covered by the sub-contract.	Training on how to create on-demand videos or podcasts offered to members, including those not covered by the sub-contract. PSR members would receive opportunity to take this training.
Develop collaborations among network members and other organizations to improve access to and sharing of biomedical information resources throughout the nation	Establish and maintain channels for effective communication with current and potential NN/LM participants, other RMLs, NLM, and other state and multi-type library networks within the region	Increased collaborations and access to biomedical information via effective communication mechanisms	One on-demand video per sub-contract	Participate in/testing/using other methods of communication, such as videoconferencing, computer conferencing;	Training on how to create on-demand videos or podcasts offered to sub-contract awardees	PSR offers funding opportunities for members to receive training and create on-demand video.
Develop collaborations among network members and other organizations to improve access to and sharing of biomedical information resources throughout the nation	Establish and maintain channels for effective communication with current and potential NN/LM participants, other RMLs, NLM, and other state and multi-type library networks within the region	Increased collaborations and access to biomedical information via effective communication mechanisms	One new technology adopted by the RML per year.	Participate in/testing/using other methods of communication, such as videoconferencing, computer conferencing.	Test videoconferencing options to replace Festoon. Explore new methods of delivering content (might include new multimedia formats, virtual reality, web 2.0, new publishing models)	Provide training and support for PSR adoption of Skype, as needed. Share results of videoconference tests with PSR. Develop communication plan for electronic communications. Provide RML web-based interactive session (open discussions, topics to be determined): 2 / year using Connect

<b>NN/LM Goal</b>	<b>GOAL</b>	<b>OUTCOMES</b>	<b>INDICATOR</b>	<b>ACTIVITY</b>	<b>MCR: Notes</b>	<b>PSR: Notes</b>
Develop collaborations among network members and other organizations to improve access to and sharing of biomedical information resources throughout the nation	Establish and maintain channels for effective communication with current and potential NN/LM participants, other RMLs, NLM, and other state and multi-type library networks within the region	Increased collaborations and access to biomedical information via effective communication mechanisms	All workgroups use alternative form of technology to meet  Note: PSR indicator probably relates to Resource Libraries	Participate in testing/using other methods of communication, such as videoconferencing, computer conferencing.	Research and test videoconferencing options to replace Festoon.	Survey Resource Library capability Research, test and implement best method for videoconferencing with Resource Libraries. Spring 2008 videoconference with RL's.
Develop, promote, and improve electronic access to health information by network members, health professionals, and organizations providing health information to the public	Develop an information technology and policy program to improve access to biomedical information	Under-connected Network Members have increased access to biomedical information and to communication tools	Technology liaisons efforts will contribute to an increase in connectivity of at least one institution per state over the contract period	Review the adequacy of the Internet connections of network members on an annual basis, reporting the results to the region and to NLM, and assisting the "under connected" in maintaining and upgrading their connections	In Year 2, two institutions in two different states other than Utah will participate in under-connected project. Note: Rebecca will coordinate this for the MCR.	At least 2 (and up to 5) institutions will participate in the under-connected project in PSR.
Develop, promote, and improve electronic access to health information by network members, health professionals, and organizations providing health information to the public	Develop an information technology program and policy issues to improve access to biomedical information	In conjunction with other RMLs, Network members, health professionals, and organizations providing health information to the public are able to learn about new technology developments that will help them to increase access to biomedical information	50% of network members surveyed indicated that have adopted at least one showcased new technology per year	Identify, evaluate and monitor the best authoritative sources for new technology information	This activity refers to time spent "keeping up" with new technologies; i.e., learning about and "playing with" new technologies as they come to my attention. If the technologies look useful for members, these are showcased to members under the "showcase information technologies..." activity.	This activity refers to time spent "keeping up" with new technologies; i.e., learning about and "playing with" new technologies as they come to my attention. If the technologies look useful for members, these are showcased to members under the "showcase information technologies..." activity.

<b>NN/LM Goal</b>	<b>GOAL</b>	<b>OUTCOMES</b>	<b>INDICATOR</b>	<b>ACTIVITY</b>	<b>MCR: Notes</b>	<b>PSR: Notes</b>
Develop, promote, and improve electronic access to health information by network members, health professionals, and organizations providing health information to the public	Develop an information technology program and policy issues to improve access to biomedical information	Members adopt new technologies to increase access to biomedical information	50% of network members surveyed indicated that have adopted at least one showcased new technology per year	Investigate and showcase information technologies and policies affecting their use on a regular basis.	Offer regular updates on technology website and newsletter Offer update at Wyoming Symposium Offer updates at Breezing along with the RML sessions Participate in Web Developer's Group	Offer regular updates on technology website (to be created for PSR) and newsletter. 2 newsletter articles by Sharon and 1 by workgroup member Offer updates to members via Connect as deemed appropriate by PSR Participate in Web Developer's Group
Develop, promote, and improve electronic access to health information by network members, health professionals, and organizations providing health information to the public	Develop an information technology program and policy issues to improve access to biomedical information	Members adopt new technologies to increase access to biomedical information.	75% of class participants indicate increased knowledge about technologies	Hold classes focused on the use of information technology to improve access to biomedical information and on policy issues affecting production, distribution, and access to biomedical information	Offer 12 classes per year on technology topics (see separate list). MCR classes are taught using Connect. Develop and offer Networking class using Moodle, with Rebecca.	Offer 4 technology classes in Year 2: two through distance, two in person (one at chapter meeting in Feb. 08, the other in-person to be determined)

<b>NN/LM Goal</b>	<b>GOAL</b>	<b>OUTCOMES</b>	<b>INDICATOR</b>	<b>ACTIVITY</b>	<b>MCR: Notes</b>	<b>PSR: Notes</b>
Develop, promote, and improve electronic access to health information by network members, health professionals, and organizations providing health information to the public	Develop an information technology program and policy issues to improve access to biomedical information	Working groups contribute to the technology project activities	At least one new idea generated by working group is integrated into the program each year	Hold regular meetings with Technology working group	Hold quarterly meetings with Technology working group. Working group members are solicited to write newsletter articles and teach classes, as well as provide information about technology projects in their state and advice to liaisons about the direction of the MCR technology project.	Form PSR Technology Working group. Hold quarterly meetings. Determine charter of the working group, perhaps the same as MCR's.
	Develop an information technology program and policy issues to improve access to biomedical information	Access to knowledge based health information is available to support healthcare during and after and emergency.	2 tests using different communications methods for 2 different scenarios are successfully conducted	Explore and test communication tools based on emergency scenarios.	Sharon is responsible for leading the Emergency Planning "web presence" working group.	No activity related to PSR for this activity.



**ATTACHMENT 2**  
**Logic Model Indicators and Activities - Status**

Indicator / Activity #1: Access Grid / PIGs

Indicator: Each Resource Library with a PIG is a participating site for at least one event using the PIG.

Activity: The RML organizes Access Grid events and helps install PIGs at Resource Libraries

Progress: This activity is an MCR activity only. Progress was made on the activity, but the indicator as written was not met. Sharon worked with the Resource Libraries to continue setting up and testing the PIGs. An event (Dan Wilson's Emergency Preparedness presentation) will be held on June 17, but we did not hold an event during the 10 month pilot period.

Indicator / Activity #2: Web site

Indicator: 75% of members responding to periodic web questionnaires indicate increased knowledge of biomedical information due to reading the regional web site.

Activity: Develop and maintain a regional Web site as an integral component of the NN/LM Web site.

Progress: Web site evaluation questionnaires were conducted for both regions. The indicator was met; over 75% of members in both regions said they increased their knowledge due to reading the web site. For PSR, the questionnaire asked broader questions about communications that will be used to inform a communications plan. For MCR, the questionnaire will be used in conjunction with the upcoming usability tests to determine what improvements should be made to the web site. In addition, Sharon assisted other staff in both regions with routine maintenance of the web site.

Indicator / Activity #3 - 5: Video on Demand

Indicators: At least three video on demand events per year provided by the RML. At least one on-demand video provided by those trained. One on-demand video per subcontract.

Activity: Participate in/testing/using other methods of communication, such as videoconferencing, computer conferencing, podcasts.

Progress: The indicator was not met. Neither region offered a video on demand event. There were no applicants for the video on demand subcontract, so no members offered an event.

#### Indicator / Activity #6: New communications technologies

Indicator: One new technology adopted by the RML per year.

Activity: Participate in/testing/using other methods of communication, such as videoconferencing, computer conferencing.

Progress: The indicator was met for both regions. Sharon continued to test new videoconferencing products, and the MCR used Skype and Adobe Connect routinely for meetings and distance education. MCR staff adopted other new technologies for communication (small group wikis). Sharon also worked with the PSR staff to communicate via Skype and to offer distance education through Abode Connect. In addition, Sharon and PSR staff had regular distance meetings using a Polycom videoconferencing system.

#### Indicator / Activity #7: New communications technologies for workgroups and Resource Libraries

Indicator: All workgroups use alternative form of technology to meet  
note: PSR indicator probably relates to Resource Libraries

Activity: Participate in testing/using other methods of communication, such as videoconferencing, computer conferencing.

Progress: This indicator was met for MCR; the technology workgroup met using Adobe Connect. Sharon tested Adobe Connect with the PSR Resource Library directors, but a meeting using the technology was not held in the 10-month period.

#### Indicator / Activity #8: Under-connected Project

Indicator: Technology liaisons efforts will contribute to an increase in connectivity of at least one institution per state over the contract period

Activity: Review the adequacy of the Internet connections of network members on an annual basis, reporting the results to the region and to NLM, and assisting the "under connected" in maintaining and upgrading their connections

Progress: The indicator was not met for either region. In the MCR, the technology liaisons held an Adobe Connect forum to discuss connectivity issues with hospital librarians (particularly firewalls and information filters).

#### Indicator / Activity #9 & 10: Evaluating and Showcasing New Technologies

Indicator: 50% of network members surveyed indicated that have adopted at least one showcased new technology per year

Activities: Identify, evaluate, and monitor the best authoritative sources for new technology information. Investigate and showcase information technologies and policies affecting their use on a regular basis.

Progress: The indicator was not met since we did not conduct a survey. Sharon regularly monitors and evaluates new technology developments and posts the information to the MCR news. She wrote two articles for the PSR Latitudes newsletter. She gave technology updates at the Wyoming Symposium in July 2007 as well as for the MCR's "Breezing Along with the RML" session. Anecdotal feedback from members in both regions indicated they appreciated the technology updates and classes.

#### Indicator / Activity # 11: Technology Classes

Indicator: 75% of class participants indicate increased knowledge about technologies.

Activity: Hold classes focused on the use of information technology to improve access to biomedical information and on policy issues affecting production, distribution, and access to biomedical information.

Progress: The indicator was met for both regions. In each class session below over 75% of the participants indicated they had increased their knowledge. Classes offered via distance education using Adobe Connect are listed below:

*The "New" Current Awareness Service: Introduction to RSS (One Hour Class):* Six sessions were taught from August – October 2007, with a total of 92 participants from PSR.

*Introduction to Blogs and Wikis (4 Hour MLA CE class):* One session was taught in October 2007 for MCR, with 7 participants. Two sessions were taught in December 2007 – January 2008 for PSR, with a total of 23 participants.

*Introduction to Personalized Google / iGoogle (One Hour Class):* Two sessions were taught in April 2008 for MCR and PSR simultaneously. Twenty-four participants attended from MCR; 51 from PSR.

In addition, Sharon consulted with both PSR and MCR members after the classes about various technology issues related to the class materials or other technology questions.

#### Indicator / Activity #12: Workgroups

Indicator: At least one new idea generated by working group is integrated into the program each year.

Activity: Hold regular meetings with Technology working group.

Progress: The indicator as written was not met. Sharon met remotely using Adobe Connect with the MCR Technology Working Group on a quarterly basis throughout the 10 month period. Several ideas were generated by the group but none were integrated into the program yet. Sharon formed the PSR Technology Advisory Group in March 2008; the first meeting was held at UCLA on May 9, 2008.

### Indicator / Activity #13: Emergency Planning

Indicator: 2 tests using different communications methods for 2 different scenarios are successfully conducted.

Activity: Explore and test communication tools based on emergency scenarios.

Progress: Sharon set up a draft emergency planning web page, which was then turned over to Dan Wilson's group.

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Attachment 4:  
Go Local Quarterly Report

University of Kansas  
Kansas Go Local

# Go Local Project Report

**Go Local Project Name:** Kansas Go Local

**Submitted by**

- **Name:** Amy Ritterskamp
- **e-mail address:** aritterskamp@kumc.edu

**Date Submitted:** July 8<sup>th</sup>, 2008

**Dates covered:** April-June 2008

**If currently receiving NN/LM funding, Contract number (optional):** 2507044-09

**A. For Sites not yet released:**

**Estimated release month/year:** January 2009

**Progress on project timeline**

- Held virtual training for Selectors in early June.
- Selectors began inputting records from their region.
- Continuing review of imported data.
- Two State Library Regions have met their goal to receive grant money.

**B. For all projects:**

**1. Major staff leaving or joining the project this quarter (name and role)**

- Mary Lou Chard, Selector from SEKLS
- Gail Santy, Selector from CKLS
- Jo Ann Warman, Selector from NWKLS
- Brandi Seamon, Selector from NWKLS

**2. Database Development & Maintenance**

Over 2,500 records in the database.

- 90% of batch-imported data has been completed and is ready for review.
- Selectors from across the state have entered close to 200 records.

**3. Website Development & Maintenance**

- No development on the web site at this time due to focusing on database

**4. Outreach and promotion efforts**

- Sent partnership proposal to Emporia University's School of Library and Information Management program to assist with review and selection. Cataloging class would provide review of records; Collection Development class would assess 'collection' for deficiencies and fill in the gaps.

- Working on partnership proposal to Kansas Regents Institutions to provide record review. Each Institution would be assigned a Region and would be responsible for reviewing records from that area.
- Still encouraging a partnership with Kansas Biomedical Librarians (Particularly Via Christi) to review records.
- Planning for KHO Days and focus groups which involves traveling around the state teaching librarians and consumers about Kansas Health Online, MedlinePlus, and Go Local Kansas as well as gathering information from consumers about their health needs. Also provides opportunity for face-to-face training of Selectors. First KHO Day will be July 16<sup>th</sup> in Iola, Kansas.

## 5. Other

- None at this time.

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Attachment 5:  
Go Local Quarterly Report

University of Nebraska  
Go Local Nebraska



## Go Local Project Name: Go Local Nebraska

Submitted by: Marie Reidelbach [mreidelb@unmc.edu](mailto:mreidelb@unmc.edu)

Date Submitted: July 3, 2008

Dates covered: April-June 2008

### **B. For all projects:**

#### 1. Major staff leaving or joining the project this quarter (name and role)

- No change in staffing

#### 2. Database Development & Maintenance

- Over 840 dental clinics were sent a letter in April requesting that the dentists verify the contents of their individual records. The letters also included a brochure about the McGoogan Library of Medicine's consumer programs and a baseball card of Go Local Nebraska. The dentists have been very responsive in contacting the library to update their information.
- Hospitals, clinics, and dental clinics are being audited for the current year.
- Respite care resources, mental health clinics, and veteran services are currently being added or updated.

#### 3. Website Development & Maintenance

- No changes.

#### 4. Outreach and promotion efforts

- Marie Reidelbach and Teri Hartman attended the Republican Valley/Meridian Library Systems' Joint Annual Meeting in Hastings, Nebraska on June 6. They presented information on Go Local Nebraska, the Consumer Health Information Resource Service [CHIRS], and other support offered by the McGoogan Library of Medicine to all public librarians in the state.
- Marie and Teri also exhibited Go Local Nebraska and the CHIRS program at the 2008 Cattleman's Ball on June 7 near Albion, Nebraska. The Ball is a major fund raiser to support cancer research at the Eppley Cancer Center at UNMC. Meeting and talking about high quality health information sources such as Go Local Nebraska, CHIRS, and MedlinePlus with some of the 3000 attendees was exciting. This exhibit was held outdoors in a tent! Lucky for the team, the weather was beautiful that day.
- CHIRS and Go Local Nebraska were discussed at the Nebraska Libraries Future Search event that was held in Schuyler, Nebraska on June 10 and 11. Nearly 100 Nebraska citizens, elected officials, librarians, and trustees agreed that having quick access to evaluated, reliable, local health information is and will continue to be important to Nebraskans.
- Go Local Nebraska and CHIRS teamed up with the National Network of Libraries of Medicine to exhibit at the Washington Branch of the Omaha Public Library on June 18 in

Omaha, Nebraska. The Omaha World Herald published a story about the event at this site: [http://omaha.com/index.php?u\\_page=3940&u\\_sid=10362060](http://omaha.com/index.php?u_page=3940&u_sid=10362060). Health information resources were presented to the adults in the crowd as they watched the kids and young people ride the rides. This was a great community event!

- The Go Local Nebraska team exhibited at the Eastern Library System Annual Meeting, held in Bellevue, Nebraska on June 20. Public, school, and special librarians attended the meeting, and stopped by the booth to catch up on the news about Go Local Nebraska and CHIRS. This was also a great opportunity to show the Go Local/CHIRS display that can be checked out by any library in Nebraska. Additionally, brochures were given to representatives of the Soul Desires and Confluence bookstores, so their customers would know about the health information services offered to them.

#### 5. Other

- [\*\*A testimonial showing how CHIRS/Go Local Nebraska make a difference\*\*](#)
  - My father has a rare disease. I needed to find the singular specialist in Omaha for a second opinion and treatment consultation. But who? And how would I find this doctor? Could there even be someone in our area?  
I emailed my request to Teresa Hartman at Go Local Nebraska, and within hours I had the name of a doctor with the subspecialty in neurology. Within a few days, we were sitting in his office. We are most grateful to the medical librarians at the McGoogan Library who know everything! You just have to ask.  
Submitted by Sandra Wendel
- More information about members of the Advisory Committee and pictures from various events is linked from the Go Local Nebraska blog: <http://golocalne.blogspot.com/>

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Attachment 6:  
Subcontractor Quarterly Report

University of Utah  
Using the “Information Rx” Process to Refer Adults and Parents  
of Children with Metabolic Conditions to the Genetics Home  
Reference Web Site for Health Information

## QUARTERLY REPORT

### COVER SHEET

1. Title of Project\*:

Using the “Information Rx” Process to Refer Parents of Newborns with Metabolic Conditions Identified by Screening to the Genetics Home Reference Web Site for Health Information

2. Name of Institution:

University of Utah, Department of Biomedical Informatics

3. Location of Institution:

26 South 2000 East  
HSEB Suite 5700  
School of Medicine  
Salt Lake City, UT 84112-5750

4. Name, Mailing and E-Mail Addresses, Voice and Fax Numbers, of Person Submitting Report:

Denise E. Beaudoin  
mailing address as above  
email address [denise.beaudoin@hsc.utah.edu](mailto:denise.beaudoin@hsc.utah.edu)  
phone 801-581-4080  
FAX 801-581-4297

5. Number and Inclusive Dates of Quarterly Report:

Quarterly Report #3, covering the period from 04/16/08 through 07/15/08

6. Submission Date:

July 15, 2008

\* Note new project title:

Using the “Information Rx” Process to Refer Adults and Parents of Children with Metabolic Conditions to the Genetics Home Reference Web Site for Health Information

## NARRATIVE DESCRIPTION

1. Executive summary. Please provide a brief, one-paragraph narrative summarizing major accomplishments made during the quarter.

Patient recruitment began on April 28, 2008. Parents of two infants diagnosed with a metabolic disorder identified by newborn screening were enrolled before the study eligibility criteria were expanded to include adults and parents of older children with metabolic conditions. Changes to the protocol summary, study description, consent form and surveys were proposed to accommodate this change and a study amendment was submitted to the University of Utah IRB for review. The study was determined to be exempt from federal regulations governing human research on May 14, 2008. Modifications to question 20 in the follow-up survey were also proposed when investigators noted the need for an additional response category. A final amendment was submitted to the IRB and the study was once again deemed exempt on June 9, 2008. To date, 40 participants have been enrolled in the study. Metabolic conditions include PKU, CG, LCHAD, MCAD and MSUD, among others.

2. Description of Progress toward the Project's Major Objectives:
  - a. Administrative/Planning Activities:
    - i. Two study amendments were submitted to the University of Utah IRB and deemed 'exempt' (please see above).
  - b. Collaborations/Partnerships: Ongoing with Dr. Longo's Metabolic Clinic staff.
  - c. Publicity/Marketing Activities: Not applicable.
  - d. Product/Resource Development Activities: Not applicable.
  - e. Site Visits: None at this time.
  - f. Outreach activities: None at this time.
  - g. Web site development activities: Not applicable.
  - h. Exhibits:
    - i. Dr. Beaudoin presented a poster describing the 'Info Rx' project at the annual meeting of the Utah Library Association in April 2008.
    - ii. Drs. Mitchell, Longo, Logan and Beaudoin submitted a poster for presentation at the annual AMIA meeting in November but were notified on June 18 that the abstract was not accepted.
3. Loansome Doc/Document Delivery Activities: Not applicable.
4. Evaluation Activities: Not applicable at this time.
5. Problems/Corrective Actions (including significant changes made in implementation of the project): After discussion among study investigators, the decision was made to expand the study eligibility criteria beyond the parents of newborns to include adults and parents of older children with metabolic conditions who are seen at the Metabolic Clinic. This change will increase the number of potential study participants and allow the investigators to obtain feedback about the GHR Web site from three distinct populations:

the parents of infants with a metabolic condition identified by newborn screening, the parents of children living with metabolic conditions, and adult patients with metabolic conditions. Although a Web-based version of the initial survey was created in order to streamline the data collection process, the paper-and-pencil version has been used as it is a better 'fit' with clinic flow.

6. Lessons Learned/Significant Feedback: Not applicable at this time.
7. Projected Activities for Next Quarter:
  - (a) Dr. Beaudoin will continue recruitment of study participants from among patients seen at the Metabolic Clinic.
  - (b) Dr. Beaudoin will conduct follow-up of study participants (by e-mail and letter) to ensure that they access the GHR Web site and complete the follow-up survey.
  - (c) Dr. Beaudoin will continue data entry and begin data analysis.
8. Reports of Training/Demonstration Sessions and/or Exhibit Reports: Not applicable.

## APPENDIX

Include copies of: communications, materials produced, evaluation tools/instruments used or developed, press releases, advertisements, articles for newsletters, etc.

Please see attached IRB correspondence, revised study documents including the most recent (paper) versions of the study description, consent form and surveys.

**IRB: IRB\_00023554**

**Principal Investigator:** Joyce Mitchell

**Title:** Using the “Information Rx” Process to Refer Parents of Newborns with Metabolic Conditions Identified by Screening to the Genetics Home Reference Web Site for Health Information

This Amendment Application (Info Rx Amendment Expanded Study 4/29/08) qualifies for an expedited review by a designated University of Utah IRB member according to University IRB policy. The designated IRB member has reviewed and approved your amendment request for this study on **5/14/2008**. The approval of this amendment request does NOT change the expiration date of this research study as noted below.

Any future changes to this study must be submitted to the IRB prior to initiation via an amendment form.

## **APPROVED DOCUMENTS**

### **Protocol Summary**

Protocol Summary Expanded Study 5/5/08 clean

### **Informed Consent Document**

Consent Form Expanded Study 4/29/08 clean

### **Surveys, etc.**

Follow-up Survey Expanded Study 5/8/08 clean

Initial Survey Expanded Study 5/5/08 clean

### **Other Documents**

Reminder Letter #2 Expanded Study 4/29/08 clean

Study Description Expanded Study 4/29/08 clean

Reminder Email #2 Expanded Study 4/29/08 clean

Reminder Letter #1 Expanded Study 4/29/08 clean

Reminder Email #1 Expanded Study 4/29/08 clean

**IRB:** IRB\_00023554

**Principal Investigator:** Joyce Mitchell

**Title:** Using the “Information Rx” Process to Refer Adult Patients and Parents of Children with Metabolic Conditions to the Genetics Home Reference Web Site for Health Information

This Amendment Application ('Info Rx' Amendment, Expanded Study Revised Survey, 5/23/08) qualifies for an expedited review by a designated University of Utah IRB member according to University IRB policy. The designated IRB member has reviewed and approved your amendment request for this study on **6/9/2008**. The approval of this amendment request does NOT change the expiration date of this research study as noted below.

Any future changes to this study must be submitted to the IRB prior to initiation via an amendment form.

## **APPROVED DOCUMENTS**

### **Surveys, etc.**

Follow-up Survey, Expanded Study, Mod Q20, 6/6/08



## Study Description

Title: Using the “Information Rx” Process to Refer Adult Patients and Parents of Children with Metabolic Conditions to the Genetics Home Reference Web Site for Health Information

Principal Investigator: Joyce A. Mitchell, PhD  
Department of Biomedical Informatics  
26 South 2000 East  
HSEB Suite 5700, School of Medicine  
University of Utah  
Salt Lake City, UT 84112-5750

Purpose: To learn about patients and parents’ reactions to getting an “information prescription” from their/their child’s physician that directs them to a Web site where they may retrieve accurate and consumer-friendly health information about their/their child’s metabolic condition, and their assessment of the information found on this site.

Criteria for eligibility:

- Parent/caregiver of a newborn or child under the age of 18 who has been diagnosed with at least one metabolic condition
- Patient age 18 or older who has been diagnosed with at least one metabolic condition
- Diagnosis was made by Nicola Longo, MD, PhD (or medical colleague) at the University of Utah Metabolic Clinic

Potential benefits of participation:

- Increased understanding about your/your child’s medical condition
- Improved communication with your/your child’s doctor

Time commitment involved:

- Completion of initial survey at the clinic (5 to 10 minutes)
- Exploration of GHR Web site on your own (variable time)
- Completion of online survey six weeks after the clinic visit (online survey should not take more than 30 minutes to complete)

Contact: Denise E. Beaudoin, MD, MSPH, MS, Department of Biomedical Informatics, University of Utah, phone: 801-581-4080

List of Metabolic Conditions\*:

Argininosuccinic acidemia (ASA)  
Beta ketothiolase deficiency (BKT)  
Biotinidase deficiency (BIOT)  
Carnitine uptake defect (CUD)  
Citrullinemia (CIT)  
Classical galactosemia (GALT)  
Glutaric acidemia type 1 (GA I)  
Homocystinuria (due to CBS deficiency) (HCY)  
3-hydroxy 3-methyl glutaric aciduria (HMG)  
Isovaleric acidemia (IVA)  
Long-chain 3-hydroxy acyl-CoA dehydrogenase deficiency (LCHAD)  
Maple syrup disease (MSUD)  
Medium-chain acyl-CoA dehydrogenase deficiency (MCAD)  
3-Methylcrotonyl-CoA carboxylase deficiency (3MCC)  
Methylmalonic acidemia (Cbl A,B)  
Methylmalonic acidemia (mutase deficiency) (MUT)  
Multiple carboxylase deficiency (MCD)  
Phenylketonuria (PKU)  
Propionic acidemia (PROP)  
Trifunctional protein deficiency (TFP)  
Tyrosinemia type I (TYR I)  
Very long-chain acyl-CoA dehydrogenase deficiency (VLCAD)

\* Other metabolic conditions may also be included

## Consent and Authorization Document

### BACKGROUND

You are being asked to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with friends and relatives if you wish. Ask the research doctor or staff if there is anything that is not clear or if you would like more information. Take time to decide whether or not to volunteer to take part in this research study.

The purpose of the study is to learn about your reaction to getting an “information prescription” from your/your child’s doctor that contains the address of a Web site with information about your/your child’s medical condition, and your assessment of the information you find on this Web site. This study is being conducted by researchers in the Biomedical Informatics and Pediatrics Departments at the University of Utah and the National Library of Medicine’s National Network of Libraries of Medicine.

### STUDY PROCEDURES

If you decide to participate in this study, you will be asked to complete two surveys. The first survey will be completed by you after your clinic visit with Dr. Nicola Longo at the Metabolic Clinic located at Primary Children’s Medical Center. This survey (Web-based or paper-and-pencil depending upon the availability of Internet access at the Clinic) will ask about your computer use and some demographics (such as your age, gender, etc.) and should take you no more than 10 minutes to complete. You will then be asked to visit the Genetics Home Reference (GHR) Web site on your own using the information written on the “Information Prescription” that you receive from Dr. Longo or one of his colleagues. Three weeks after your clinic visit, you will receive a letter in the mail and an e-mail if you have an e-mail address reminding you to visit the GHR Web site. Six weeks after your clinic visit, you will receive another letter and e-mail, asking you to go to the GHR Web site to complete an online survey about your experience. The online survey will consist of 30 questions. You will be asked to complete this survey at one sitting. This survey should take no more than 30 minutes to complete. The total length of time that you will be involved in this study is approximately six weeks.

### RISKS

A breach of confidentiality is possible; however, every effort will be made by the researchers to keep any information that you provide confidential.

### BENEFITS

We cannot promise any benefits to you from your being in the study. However, possible benefits may include increased understanding about your/your child’s medical condition and improved communication with your/your child’s doctor. You will receive a summary report of the study results.

### CONFIDENTIALITY

Results of the study may be published; however, your name and other identifying information will be kept private. We will keep all research records that identify you private to the extent allowed by law. Records about you will be kept in locked filing cabinets, or on computers protected with passwords. Only those who work with this study will be allowed access to your information.

## **PERSON TO CONTACT**

If you have questions, complaints or concerns about this study, you can contact Dr. Denise Beaudoin at 801-581-4080. If you think you may have been injured from being in this study, please call Dr. Denise Beaudoin at 801-581-4080 during the day from 9 am to 5 pm, Monday through Friday.

## **INSTITUTIONAL REVIEW BOARD**

Contact the Institutional Review Board (IRB) if you have questions regarding your rights as a research participant. Also, contact the IRB if you have questions, complaints or concerns which you do not feel you can discuss with the investigator. The University of Utah IRB may be reached by phone at (801) 581-3655 or by e-mail at [irb@hsc.utah.edu](mailto:irb@hsc.utah.edu).

## **RESEARCH-RELATED INJURY**

If you are injured from being in this study, medical care is available to you at the University of Utah as it is to all sick or injured people. The University of Utah does not have a program to pay you if you are hurt or have other bad results from being in the study. The costs for any treatment or hospital care would be charged to you or your insurance company (if you have insurance), to the study sponsor or other third party (if applicable), to the extent those parties are responsible for paying for medical care you receive. Since this is a research study, some health insurance plans may not pay for the costs.

The University of Utah is a part of the government. If you are injured in this study, and want to sue the University or the doctors, nurses, students, or other people who work for the University, special laws may apply. The Utah Governmental Immunity Act is a law that controls when a person needs to bring a claim against the government, and limits the amount of money a person may recover. See Section 63-30d-101 through 63-30d-904 of the Utah Code.

## **VOLUNTARY PARTICIPATION**

It is up to you to decide whether or not to take part in this study. If you decide to take part you are still free to withdraw at any time and without giving a reason. Refusal to participate or the decision to withdraw from this study will involve no penalty or loss of benefits to which you are otherwise entitled. If you don't take part, you can still receive all standard care that is available to you. This will not affect the relationship you have with your doctor or other staff, nor decrease the standard of care that you receive as a patient.

## **UNFORESEEABLE RISKS**

None.

## **COSTS AND COMPENSATION TO PARTICIPANTS**

There are no costs to you if you decide to participate in this study. You will not be compensated for your time.

## **NUMBER OF PARTICIPANTS**

We expect to enroll from 60 to 120 participants from among the adult patients and the parents/caregivers of newborns/children under the age of 18 who have been diagnosed with at least one metabolic condition by Dr. Nicola Longo at the Metabolic Clinic located at Primary Children's Medical Center. This is a pilot study; the results obtained in Utah may influence whether this study is undertaken by researchers in other states.

## **AUTHORIZATION FOR USE OF YOUR PROTECTED HEALTH INFORMATION**

Signing this document means you allow us, the researchers in this study, and others working with us to use information about your health for this research study. You can choose whether or not you will participate in this research study. However, in order to participate you have to sign this consent and authorization form.

This is the information we will use:

- Your name
- Your current age
- Your date of birth
- Your gender
- Your highest level of education
- Your race/ethnicity
- Your street address, city, state and zip code
- Your telephone numbers (home and cell if available)
- Your e-mail address (if you have one)
- Your role in your child's medical care (if applicable)
- The name of your child (if applicable)
- The birth date of your child (if applicable)
- The name of your/your child's physician
- The name of your/your child's metabolic condition
- The date of your/your child's diagnosis for this metabolic condition

Others who will have access to your information for this research project are the University's Institutional Review Board (the committee that oversees research studying people) and authorized members of the University of Utah Health Sciences Center and Primary Children's Hospital who need the information to perform their duties (for example: to provide treatment, to ensure integrity of the research, and for accounting or billing matters).

If we share your information with anyone outside the University of Utah Health Sciences Center or the Metabolic Clinic located at Primary Children's Medical Center, you will not be identified by name, social security number, address, telephone number, or any other information that would directly identify you, unless required by law.

You may revoke this authorization. **This must be done in writing.** You must either give your revocation in person to the Principal Investigator or the Principal Investigator's staff, or mail it to Joyce Mitchell, PhD, Professor and Chair, Dept of Biomedical Informatics, 26 South 2000 East, HSEB suite 5700, School of Medicine, University of Utah, Salt Lake City, UT 84112-5750. If you revoke this authorization, we will not be able to collect new information about you, and you will be withdrawn from the research study. However, we can continue to use information we have already started to use in our research, as needed to maintain the integrity of the research. This authorization does not have an expiration date.

**CONSENT**

I confirm that I have read this consent and authorization document and have had the opportunity to ask questions. I will be given a signed copy of the consent and authorization form to keep.

**I agree to take part in this research study and authorize you to use and disclose health information about me for this study, as you have explained in this document.**

\_\_\_\_\_  
Participant's Name

\_\_\_\_\_  
Participant's Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Name of Person Obtaining Authorization and Consent

\_\_\_\_\_  
Signature of Person Obtaining Authorization and Consent

\_\_\_\_\_  
Date

## Using the "Information Rx" Process to Refer Adult Patients and Parents of Children with Metabolic Conditions to the Genetics Home Reference Web Site for Health Information

### Initial Parent Survey

Please select one answer to each of the following questions:

1. How frequently do you look up sources of medical information?
  - Very frequently
  - Somewhat frequently
  - Neither frequently nor infrequently
  - Somewhat infrequently
  - Very infrequently
  
2. How frequently do you discuss the medical information that you look up with your/your child's doctor?
  - Very frequently
  - Somewhat frequently
  - Neither frequently nor infrequently
  - Somewhat infrequently
  - Very infrequently
  
3. Do you find it easy or difficult to understand the medical issues that your/your child's doctor discusses with you?
  - Very easy
  - Somewhat easy
  - Neither easy nor difficult
  - Somewhat difficult
  - Very difficult
  
4. Do you find it easy or difficult to read health information on a computer compared to a book or pamphlet?
  - Very easy
  - Somewhat easy
  - Neither easy nor difficult
  - Somewhat difficult
  - Very difficult
  
5. Where is the location of the nearest computer you can use?
  - At home
  - At the office
  - At a school
  - At a public library
  - At a hospital library
  - At another family member's location
  - Other (please fill in): \_\_\_\_\_
  
6. On average, about how many hours a day (both at home and work) do you check for email and use the Internet for all other purposes?
  - 0 to 1 hour
  - 2 to 4 hours
  - 5 to 6 hours
  - More than 6 hours

7. Had you ever visited the Genetics Home Reference Web site prior to receiving the Information Prescription from your/your child's doctor today?
- Yes
  - No
  - Don't know
8. If yes, approximately how many times have you visited the Genetics Home Reference Web site?
- Once
  - Twice
  - Three to five times
  - More than five times
  - I have visited the site before but don't know how many times
  - I have never visited the Genetics Home Reference Web site
9. How did you first learn about the Genetics Home Reference Web site?
- From my/my child's doctor at today's clinic visit
  - From another doctor
  - From the staff in my/my child's doctor's office
  - From an ad
  - From friends and family
  - From an Internet search
  - From a local librarian
  - From either a newspaper or a local radio/television station
  - Other (please fill in): \_\_\_\_\_

**Please tell us if you agree or disagree with the following statement:**

10. I think receiving a prescription from my/my child's doctor to visit the Genetics Home Reference Web site for more information is a good idea.
- Strongly agree
  - Somewhat agree
  - Neither agree nor disagree
  - Somewhat disagree
  - Strongly disagree
11. Did you receive enough information today from your/your child's doctor to feel comfortable about using the Genetics Home Reference Web site?
- Yes
  - No
  - Don't know

**We'd like to know a little more about you and your child...Please go directly to question 16 if you are completing this survey about yourself.**

12. What is your child's name? \_\_\_\_\_
13. What is your child's date of birth? \_\_\_\_\_
14. What is your role in this child's medical care?
- Parent
  - Guardian/caretaker
  - Other (please explain): \_\_\_\_\_
15. What is the name of your child's physician? \_\_\_\_\_



16. What is your name? \_\_\_\_\_

17. What is your age? \_\_\_\_\_

18. What is your date of birth? \_\_\_\_\_

19. What is your gender?

- Male
- Female

20. Which of the following best describes the highest level of education you have completed?

- Did not complete high school
- High school graduate or equivalent (GED)
- Some college or vocational school
- College graduate
- Some postgraduate school
- Graduate/professional degree

21. Which of the following best describes your race/ethnicity?

- American Indian or Alaskan Native
- Asian or Pacific Islander
- Black not of Hispanic origin
- Hispanic
- White not of Hispanic origin
- Other (please describe): \_\_\_\_\_

**We will contact you in three weeks to remind you to visit the Genetics Home Reference Web site and again in six weeks to remind you to complete the online survey. Please provide us with your home mailing address, telephone number(s) and e-mail address.**

22. What is your street address?  
\_\_\_\_\_

23. Which city do you live in? \_\_\_\_\_

24. Which state do you live in?

- Utah
- Idaho
- Wyoming
- Other (please fill in): \_\_\_\_\_

25. What is your 5 digit zip code? \_\_\_\_\_

26. What is your home telephone number (including area code)? For example, 801-332-9245.  
\_\_\_\_\_

27. What is your cell phone number if you have one (including area code)? For example, 801-332-9245.  
\_\_\_\_\_

28. What is your e-mail address if you have one? \_\_\_\_\_

This completes the survey. The remaining two questions are for office use only.

For office use only:

Assigned ID#: \_\_\_\_\_

Date of survey completion: \_\_\_\_\_

**Thank you very much for completing this survey. Your feedback is very important to us as it will help improve the Genetics Home Reference Web site.**

**Using the “Information Rx” Process to Refer Adult Patients and Parents of Children with  
Metabolic Conditions to the Genetics Home Reference Web site  
for Health Information**

**Patient Follow-up Survey**

ID# \_\_\_\_\_

1. I am answering the questions in this survey:
- About myself
  - About a child in my care
2. For which condition(s) did you/your child receive a confirmed diagnosis? (Please check all that apply)
- Argininosuccinic acidemia (ASA)
  - Beta ketothiolase deficiency (BKT)
  - Biotinidase deficiency (BIOT)
  - Carnitine uptake defect (CUD)
  - Citrullinemia (CIT)
  - Classical galactosemia (GALT)
  - Glutaric acidemia type 1 (GA I)
  - Homocystinuria (due to CBS deficiency) (HCY)
  - 3-hydroxy 3-methyl glutaric aciduria (HMG)
  - Isovaleric acidemia (IVA)
  - Long-chain 3-hydroxy acyl-CoA dehydrogenase deficiency (LCHAD)
  - Maple syrup disease (MSUD)
  - Medium-chain acyl-CoA dehydrogenase deficiency (MCAD)
  - 3-Methylcrotonyl-CoA carboxylase deficiency (3MCC)
  - Methylmalonic acidemia (Cbl A,B)
  - Methylmalonic acidemia (mutase deficiency) (MUT)
  - Multiple carboxylase deficiency (MCD)
  - Phenylketonuria (PKU)
  - Propionic acidemia (PROP)
  - Trifunctional protein deficiency (TFP)
  - Tyrosinemia type I (TYR I)
  - Very long-chain acyl-CoA dehydrogenase deficiency (VLCAD)
  - Other: \_\_\_\_\_
  - Don't know **Please go directly to question 4.**
  - My child had a positive screening test but was not ultimately diagnosed with one of the above conditions (false positive test) **Please go directly to question 4.**
3. When were you/was your child first diagnosed with the above condition(s)? For example, if you were/your child was first diagnosed on April 3, 2008, you would enter: 04/03/2008. If you can't remember the exact date, please provide your best estimate.
- \_\_\_\_    \_\_\_\_    \_\_\_\_\_  
mm    dd    yyyy
4. Approximately how many times have you visited the Genetics Home Reference Web site since you received the 'Information Prescription' from your doctor?
- Only once
  - Twice
  - Three to five times
  - More than five times
  - I have visited the site but don't know how many times
  - I have never visited the Genetics Home Reference Web site

If you have never visited the Genetics Home Reference Web site, please go directly to question 27.

5. Overall, was the information within the Genetics Home Reference Web site easy or difficult to understand?
- Very easy
  - Somewhat easy
  - Neither easy nor difficult
  - Somewhat difficult
  - Very difficult
6. Overall, how helpful was the information on the Genetics Home Reference Web site relating to your/your child's condition(s)?
- Very helpful
  - Somewhat helpful
  - Neither helpful nor unhelpful
  - Somewhat unhelpful
  - Very unhelpful
7. How did you use or do you plan to use the health information found on the Genetics Home Reference Web site? (Please check all that apply)
- Discussed, or will discuss, with my/my child's doctor
  - Discussed, or will discuss, with family or friends
  - Has improved my understanding of an illness or health condition
  - Has influenced, or may influence, future health decisions for myself or my child
  - Have contacted, or will contact, a support group in my area
  - Looked for, or will consider looking for, more health information
  - Other \_\_\_\_\_ (Please fill in)

**For questions 8 through 11, please rate your level of agreement with the statement:**

8. I trust the information on the Genetics Home Reference Web site because my/my child's doctor prescribed it.
- Strongly agree
  - Somewhat agree
  - Neither agree nor disagree
  - Somewhat disagree
  - Strongly disagree
9. A high-quality source of health information helps me talk to my/my child's doctor.
- Strongly agree
  - Somewhat agree
  - Neither agree nor disagree
  - Somewhat disagree
  - Strongly disagree
10. The health information that I find on the Genetics Home Reference Web site will help me make better health decisions for myself/my child.
- Strongly agree
  - Somewhat agree
  - Neither agree nor disagree
  - Somewhat disagree
  - Strongly disagree

11. The information I received on the Genetics Home Reference Web site added to what doctors told me about my/my child's condition.

- Strongly agree
- Somewhat agree
- Neither agree nor disagree
- Somewhat disagree
- Strongly disagree

12. Overall, how satisfied were you with the health information you found on the Genetics Home Reference Web site?

- Very satisfied
- Somewhat satisfied
- Neither satisfied nor dissatisfied
- Somewhat dissatisfied
- Very dissatisfied

13. Was it easy or difficult to find the information you were seeking?

- Very easy
- Easy
- Neither easy nor difficult
- Difficult
- Very difficult

14. Did you notice any missing information about your/your child's metabolic condition in the Genetics Home Reference Web site?

- Yes
- No
- Don't remember

If you selected "No" or "Don't remember" please go directly to [question 18](#).

15. If yes, please let us know briefly what information was missing when you searched for information on the Genetics Home Reference Web site. (Please write your comments below)

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16. In which general area of the Genetic Home Reference Web site did you notice that information was missing? (Please check all that apply):

- An overall explanation of the condition
- The genes that are related to or cause the condition
- How persons inherit the condition
- Where to find more information about treatment for the condition
- Where to find additional information about the condition
- Other names people use for the condition
- A gateway to getting specific questions answered about the condition
- Glossary definitions that help with understanding the condition
- Information about diagnosis
- All the above
- None of the above

17. Did you use these Internet sources to fill in the missing information?

(Please check all that apply)

- The WebMD.com Web site
- The MedlinePlus.gov Web site
- The MSN Health Web site
- The Genetic Alliance Web site
- The Ask the Geneticist Web site
- The Madisons Foundation Web site
- The March of Dimes Web site
- None of the above

**18. Please tell us how frequently you visited each of the following when you used the Genetics Home Reference Web site:**

How frequently did you visit pages that focus on a single genetic condition?

- Very frequently
- Frequently
- Neither frequently nor infrequently
- Infrequently
- Very infrequently
- Did not use

How frequently did you visit pages that focus on a particular gene?

- Very frequently
- Frequently
- Neither frequently nor infrequently
- Infrequently
- Very infrequently
- Did not use

How frequently did you visit pages that focus on a particular chromosome?

- Very frequently
- Frequently
- Neither frequently nor infrequently
- Infrequently
- Very infrequently
- Did not use

How frequently did you visit the 'Help Me Understand Genetics Handbook' (background information about genetics, including inheritance, genetic counseling)?

- Very frequently
- Frequently
- Neither frequently nor infrequently
- Infrequently
- Very infrequently
- Did not use

How frequently did you visit the definitions of glossary terms?

- Very frequently
- Frequently
- Neither frequently nor infrequently
- Infrequently
- Very infrequently
- Did not use

How frequently did you visit "Resources" (with links to other online genetic resources)?

- Very frequently
- Frequently
- Neither frequently nor infrequently
- Infrequently
- Very infrequently
- Did not use

19. Which of these areas was most helpful to you within the Genetics Home Reference Web site?

- "Genetic Conditions" (information about a single genetic condition)
- "Genes" (information about a particular gene)
- "Chromosomes" (information about a particular chromosome)
- "Handbook"
- "Glossary"
- "Resources"
- None of the above

20. **Please answer yes or no to the following questions.**

Within the Genetics Home Reference Web site:

Was "Resources" (with links to other online genetic resources) more helpful to you than "Genetic Conditions" (information about a single genetic condition)?

- Yes
- No
- Did not use area(s)

Was "Resources" (with links to other online genetic resources) more helpful to you than "Genes" (information about a particular gene)?

- Yes
- No
- Did not use area(s)

Was "Resources" (with links to other online genetic resources) more helpful to you than "Chromosomes" (information about a particular chromosome)?

- Yes
- No
- Did not use area(s)

Was "Resources" (with links to other online genetic resources) more helpful to you than "Handbook"?

- Yes
- No
- Did not use area(s)

Was "Resources" (with links to other online genetic resources) more helpful to you than the "Glossary"?

- Yes
- No
- Did not use area(s)

21. Among the links to resources that provide other genetic information and organizations outside of the Genetics Home Reference Web site, which site was most helpful to you?

- The WebMD.com Web site
- The MedlinePlus.gov Web site
- The MSN Health Web site
- The Genetic Alliance Web site
- The Ask the Geneticist Web site
- The Madisons Foundation Web site
- The March of Dimes Web site
- None of the above

22. **Please rate your level of agreement with the following statements:**

The Genetics Home Reference Web site was more helpful to me than the WebMD.com Web site.

- Strongly agree
- Somewhat agree
- Neither agree nor disagree
- Somewhat disagree
- Strongly disagree
- Did not use

The Genetics Home Reference Web site was more helpful to me than the MedlinePlus.gov Web site.

- Strongly agree
- Somewhat agree
- Neither agree nor disagree
- Somewhat disagree
- Strongly disagree
- Did not use

The Genetics Home Reference Web site was more helpful to me than the MSN Health Web site.

- Strongly agree
- Somewhat agree
- Neither agree nor disagree
- Somewhat disagree
- Strongly disagree
- Did not use

The Genetics Home Reference Web site was more helpful to me than the Genetic Alliance Web site.

- Strongly agree
- Somewhat agree
- Neither agree nor disagree
- Somewhat disagree
- Strongly disagree
- Did not use

The Genetics Home Reference Web site was more helpful to me than the Ask the Geneticist Website.

- Strongly agree
- Somewhat agree
- Neither agree nor disagree
- Somewhat disagree
- Strongly disagree
- Did not use



The Genetics Home Reference Web site was more helpful to me than the Madisons Foundation Web site.

- Strongly agree
- Somewhat agree
- Neither agree nor disagree
- Somewhat disagree
- Strongly disagree
- Did not use

The Genetics Home Reference Web site was more helpful to me than the March of Dimes Web site.

- Strongly agree
- Somewhat agree
- Neither agree nor disagree
- Somewhat disagree
- Strongly disagree
- Did not use

23. How likely are you to use the Genetics Home Reference Web site again?

- Very likely
- Likely
- Neither likely nor unlikely
- Unlikely
- Very unlikely

24. How likely are you to recommend the Genetics Home Reference Web site to others?

- Very likely
- Likely
- Neither likely nor unlikely
- Unlikely
- Very unlikely

25. Please let us know what area, or link, you found the most helpful when you used the Genetics Home Reference Web site. (Please write your comments below)

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26. Please feel free to add other comments about the Genetics Home Reference Web site:

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**Please skip questions 27 and 28 and go directly to [question 29](#). (Questions 27 and 28 are intended to be answered by those who have never visited the Genetics Home Reference Web site.)**

27. If you have NEVER visited the Genetics Home Reference Web site, please tell us the reason(s).  
(Please check all that apply)

- I do not have access to a computer and the Internet
- I do not use the Internet because it is too complicated
- It's difficult for me, at times, to understand written health information
- English is not my first language
- I prefer another Internet source for health information rather than the Genetics Home Reference Web site
- It's upsetting to read about an illness that affects me/my child
- I already know enough about the medical issues my/my child's doctor asked me to look up
- What the doctors tell me is sufficient
- It's just not my nature to read about medical issues
- I forgot
- I have not had time
- Other: \_\_\_\_\_ (Please fill in)

28. Would it increase your interest in using the Genetics Home Reference Web site to know that many local libraries will:

- \* provide free access to the Internet for patients who do not have their own computers,
  - \* help patients locate health information using the Genetics Home Reference Web site,
  - \* demonstrate the Genetics Home Reference Web site to you?
- Very much
  - Somewhat
  - Not at all

29. Do you use any of the following health information resources? (Please check all that apply)

- Health care providers
- Friends and/or family members
- Other Web sites (please list): \_\_\_\_\_
- Medical journals
- Print media (newspapers/magazines)
- Radio/television programs
- Other (please list): \_\_\_\_\_

30. Did you search on any of the following Internet services to find health information about your/your child's condition? (Please check all that apply)

- Yahoo
- Google
- AOL
- Answers.com
- Other Internet services
- None of the above

31. Compared to all other health information sources you use at this time (regardless if they are or are not located on the Internet) how frequently will you use the Genetics Home Reference Web site in the future?

- Very frequently
- Frequently
- Neither frequently nor infrequently
- Infrequently
- Very infrequently
- Never

**Thank you very much for taking the time to complete this survey about the Genetics Home Reference Web site. Your feedback will help improve the site.**