

## FINAL REPORT

### COVER SHEET

1. Title of Project:  
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
2. This project was not part of a special funding initiative.
3. Name of Institution: University of Utah, Department of Biomedical Informatics
4. 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. Inclusive Date of Final Report: January 2, 2010
6. Date submitted: December 22, 2009

## FINAL REPORT

### NARRATIVE DESCRIPTION

1. **Executive Summary: Summarize the project's major accomplishments.**  
Use of a physician-directed Information Prescription (IP) to visit the Genetics Home Reference Web site (GHR) was well received by pilot study participants at a metabolic clinic. Respondents expressed a high level of satisfaction with GHR, and retrieved information was perceived as useful in key areas. Referral to GHR may enhance medical management by improving understanding of health conditions, encouraging communication with providers and prompting further health information-seeking behaviors.
2. **Geographic region/number of counties: List the geographic regions or all the counties that were impacted by the project.**  
Patients receiving clinical services at the University of Utah Metabolic Service Clinic were eligible to enroll in the study. The majority of study participants were Utah residents although eight participants were residents of nearby states (seven from Idaho and one from Nevada).
3. **Collaborations/Partnerships: Include names and types of organizations with which there was collaboration at any time during the project. Provide the current status of the partnerships, challenges encountered and lessons learned.**  
University of Utah, Division of Medical Genetics, Metabolic Service Clinic:  
The collaboration is ongoing due to manuscript preparation. Dr. Longo, colleagues and clinic staff were very helpful during the implementation phase of the project. Although initial plans called for study participants to complete a Web-based survey following the clinic visit, the plans were changed to better accommodate clinic work flow. As a result, study participants completed a paper survey at the clinic after the patient visit was concluded which worked well for all involved.
4. **Training:** Not applicable.
5. **Training sites:** Not applicable.
6. **Exhibits: List all exhibits connected with the project (if applicable). Include the meeting name, dates, location, estimated number of contacts made, demonstrations given and general impressions of success.**  
Poster 1: Using the "Info Rx" Process to Refer Parents of Newborns with Metabolic Conditions to the Genetics Home Reference Web Site, presented at the Utah Library Association/Mountain Plains Library Association annual meeting, Salt Lake City, UT, April 30-May 1, 2008. The poster findings were viewed with interest by meeting attendees.  
Poster 2: Online Information Prescriptions: Referring Patients with Metabolic Conditions to Genetics Home Reference, presented at the American Medical Informatics Association annual meeting, San Francisco, CA, November 14-18, 2009. Several physicians who attended the

## FINAL REPORT

Page 2

poster session did not have prior knowledge of GHR but were interested in referring patients to the site for health information. I provided them with information about GHR and “InfoRx” prescription pads for use with future patients.

7. **Resource materials:** Not applicable.
8. **Web sites: Detail the current status of web sites created as part of the project. Include URL, plans for future maintenance and impact.**  
This study was an evaluation of an existing Web site (Genetics Home Reference) and no new Web site was created.
9. **Document delivery and reference services: If document delivery services and reference services were provided, please provide appropriate statistics:** Not applicable.
10. **Approaches and interventions used: Describe the specific steps or activities used in the following areas: identifying and scheduling sessions:** Not applicable;  
**promotion/marketing:** Not applicable; **training:** Not applicable; **personnel/staffing:** Not applicable; **web site development:** Not applicable.
11. **Evaluation: (a) How was the project evaluated? (b) What results were achieved based on the objectives of the project?**  
(a) Two survey instruments, administered in a pre-post fashion where the intervention was the IP and subsequent visit to GHR, were developed to collect outcome data. A 28-item paper survey (administered at the initial clinic visit) sought to characterize respondents’ behaviors regarding searching for/using health information retrieved online, as well as more broadly assess Internet use. Demographic information was also collected for follow-up purposes. The second 31-item online survey (completed after receiving the IP) focused on user experience with GHR and perceived utility of information retrieved from the site.  
(b) Fifty-three of the initial 82 enrollees completed both surveys, for an overall survey response rate of 64.4%. Survey respondents were enthusiastic about the IP. In fact, 47 of the 53 persons who completed both surveys (88.7%) agreed that receiving an IP was a good idea, and all but two used the IP to visit GHR. Sixty percent of respondents reported an improved understanding of an illness or health condition. A high proportion of respondents agreed that information on GHR was trustworthy and of high quality, and 86.0% reported that they looked for or would consider looking for more health information as a result of visiting GHR. Overall, 86.0% of respondents said they were satisfied with the health information found on GHR, and 80.0% would recommend the site to others.
12. **Problems or barriers encountered: Provide details on problems encountered in the areas of promotion/marketing:** Not applicable; **training:** Not applicable;

## FINAL REPORT

Page 3

**equipment/telecommunications:** Not applicable; **personnel/staffing:** Not applicable; and **web site development:** Not applicable.

13. **Continuation plans: Report on how you plan to continue the project. Will all or some of the project's activities continue? Who will provide the funding and staffing to do so?**

The no-cost extension period for this project ended on November 30, 2009. I am not aware of current plans to continue project activities in Utah.

14. **Impact: Include information on the perceived and actual impact of the project on the library, institution or consortium. This can include the effect of the project on the library's image, increased utilization of the library, etc.**

Awareness of the GHR Web site among the medical director, colleagues and staff at the Metabolic Service Clinic was enhanced; we anticipate that this will translate into enhanced awareness among the patients (and their family members and friends) served by this clinic. Information regarding how to obtain additional free "Information Prescription" pads will be provided to the Clinic's Medical Director. As mentioned in #6 above, study findings have been disseminated at two conferences, and a manuscript is in preparation for journal submission.

15. **Recommendations for improvement: Include suggestions for alternative methods, training materials, promotional materials, etc.**

Study enrollees were given six weeks to visit GHR and complete the online survey. E-mail and letter "reminders" were sent at three weeks and again at the end of the six week time period. If I were to repeat the study, I would still send the 'reminder' e-mails and letters, but I would also call participants to remind them to visit GHR and complete the online survey. I discovered that when I spoke with participants on the phone (at the end of the follow-up period in the present study), survey completion rates improved markedly compared to results obtained with e-mails and letters alone. It seems that the "personal touch" may still be the most effective.

## FOLLOW-UP QUESTIONS

1. **Were your original project goals and objectives met? If not, why not?**

The objectives of this pilot study were to assess the reaction of adult patients and parents of children with metabolic conditions to a physician-directed 'Information Prescription' to visit GHR, and the perceived utility of information study participants found on the site. Both objectives were successfully met.

2. **(a) What significant lessons were learned which would be of interest or use to others conducting outreach projects? (b) Which strategies were the most effective in implementing the project?**

## FINAL REPORT

Page 4

(a) Patients will access online genetic health information when directed by a trusted health care provider to a reliable resource such as GHR.

(b) Effective strategies included the following: 1. Pre-testing both instruments with a cohort of parents with special needs children was very helpful and provided useful feedback for survey improvement. 2. Requiring the clinic physician to write the name of the patient's medical condition on the paper IP likely facilitated information retrieval on GHR by study participants (38/50 or 76% of respondents found it "very" or "somewhat" easy to find the information they were seeking on GHR). 3. Assigning a unique ID number to each study participant upon enrollment at the clinic visit and instructing them to enter this number in the designated field of the online survey allowed linkage of the pre and post intervention surveys, enhancing data capture.

3. **If you were to start all over again, what, if anything, would you change about your goals, project plans, etc.?**

Please see Narrative Description, #15 above.

4. **What advice or recommendations would you give to anyone considering a similar outreach effort?**

I enjoyed working with the staff and patients at the Metabolic Service Clinic and would recommend moving forward with outreach efforts intended for this patient population. I would advise anyone who is considering conducting an outreach effort within a clinical setting to meet with medical personnel and clinic staff before implementation to ensure that proposed study protocols and logistics do not increase workload but rather are well integrated into the existing work flow of the clinic.

5. **Please describe plans for disseminating lessons learned and other information about the project, such as through a conference presentation or publication. In accordance with the NIH Public Access Policy (<http://publicaccess.nih.gov>), project directors are asked to submit voluntarily to the NIH manuscript submission (NIHMS) system (<http://www.nihms.nih.gov>) at PubMed Central (PMC) final manuscripts upon acceptance for publication.**

To date, study findings have been presented at two conferences (please see Narrative Description, #6). A manuscript is currently in preparation and, once finalized, will be submitted to the Journal of the Medical Library Association for publication consideration.