

## QUARTERLY 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. Name of Institution:

University of Utah, Department of Biomedical Informatics

3. Location of Institution:

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5. Number and Inclusive Dates of Quarterly Report:

Quarterly Report #9, covering the period from 10/16/09 through 12/31/09

6. Submission Date:

December 22, 2009

## NARRATIVE DESCRIPTION

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

Dr. Beaudoin presented a poster describing study findings at the 2009 annual meeting of the American Medical Informatics Association in San Francisco in November (please see Appendix). She has prepared a draft manuscript and received comments and suggestions for improvement from study co-authors. Dr. Beaudoin plans to submit a revised manuscript to the JMLA for publication consideration.

2. Description of Progress toward the Project's Major Objectives:
  - a. Administrative/Planning Activities: The no-cost extension period for this project ended on November 30, 2009. A final project report was submitted on December 22, 2009.
  - b. Collaborations/Partnerships: Ongoing with Drs. Longo and Jones.
  - 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: Not applicable.
3. Loansome Doc/Document Delivery Activities: Not applicable.
4. Evaluation Activities: Please see final project report.
5. Problems/Corrective Actions (including significant changes made in implementation of the project): None to report.
6. Lessons Learned/Significant Feedback: Please see final project report.
7. Projected Activities for Next Quarter: Not applicable.
8. Reports of Training/Demonstration Sessions and/or Exhibit Reports: Not applicable.

## APPENDIX



# Online Information Prescriptions: Referring Patients with Metabolic Conditions to Genetics Home Reference

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**Introduction:** An Information Prescription (IP) is the provision of specific information to patients to help them manage health problems.<sup>1</sup> Physicians typically use IPs to direct patients to trustworthy Web sites.<sup>2</sup> Parents may be more likely to seek information online about their child's condition when this approach is suggested by a health professional.<sup>3</sup> The GHR (Figure 1) was developed by the National Library of Medicine (NLM) to offer consumers and providers reliable health information about genetic and metabolic conditions.<sup>4</sup>

**Objectives:** To determine reaction to a physician-directed IP to visit GHR, and perceived utility of retrieved information.

### Methods:

- Prospective pilot study
- Convenience sample of adult patients and parents of children with metabolic conditions seen at University of Utah Metabolic Service Clinic between April and November 2008
- Protocol
  - (a) Distribution of IP, invitation to enroll, informed consent
  - (b) Completion of 28-item pre-intervention, paper survey
  - (c) Visit to GHR during six weeks post clinic visit
  - (d) E-mail and letter "reminders" at three and six weeks
  - (e) Completion of 31-item post-intervention, online survey (hosted on secure Web site managed by NLM)
- Demographic data and reaction to IP from pre-intervention survey, all other results from post-intervention survey
- Reported results based on completion of both surveys

**Table 1: Selected demographics of survey respondents (N = 53)**

Role		N	%
Role	Parent/guardian	50	94.3%
	Adult patient	3	5.7%
Gender	Male	14	26.4%
	Female	39	73.6%
Age in years	Median 33 (range 20 – 46)		
Race/ethnicity	White, not of Hispanic origin	49	92.5%
	Other (Other, Hispanic, White/Hispanic)	4	7.6%
Education	High school graduate/equivalent	2	3.8%
	Some college/vocational school	21	39.6%
	College graduate	13	24.5%
	Some GSI/Graduate/professional degree	17	32.1%

**Figure 1. Screenshot of GHR home page at <http://www.ghr.nlm.nih.gov/>**

The screenshot shows the Genetics Home Reference website interface. It features a search bar at the top right and a navigation menu with categories like 'What's New', 'Genetic Disorders A to Z', 'Handbook', 'Glossary', and 'Resources'. The 'Genetic Disorders A to Z' section highlights 'Genetic Conditions' and 'Genes'. The 'Handbook' section offers information on mutations, inheritance, and genetic counseling. The 'Glossary' provides medical and genetics definitions, and 'Resources' links to other genetics information and organizations.

**Table 2: Respondent level of agreement with statements about GHR**

Statement	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
I trust the information on the GHR Web site because my/my child's doctor prescribed it.	0/50 (0%)	0/50 (0%)	2/50 (4.0%)	17/50 (34.0%)	31/50 (62.0%)
A high-quality source of health information helps me talk to my/my child's doctor.	0/50 (0%)	0/50 (0%)	3/50 (6.0%)	14/50 (28.0%)	33/50 (66.0%)
The health information that I find on the GHR Web site will help me make better health decisions for myself/my child.	0/50 (0%)	1/50 (2.0%)	8/50 (16.0%)	20/50 (40.0%)	21/50 (42.0%)
The information I received on the GHR Web site added to what doctors told me about my/my child's condition.	0/49 (0%)	1/49 (2.0%)	9/49 (18.4%)	17/49 (34.7%)	22/49 (44.9%)

### Sample comments from users of GHR

"This web site was very informative and easy to understand."  
 "I work with families who have children with special needs. I plan to give this site information to those families that this applies to. I feel that it may help them understand their child's condition. Especially those who, for whatever reason, didn't get enough information from their child's physician."  
 "I really think it is a great site and will help a lot of people. I only wish we would have had something like this when I was born so my parents could have read and talked to others who have experienced my condition."

### Results:

- 53/82 study enrollees completed both surveys, for an overall response rate of 64.4%
- Survey respondents (N = 53) tended to be parents, female and highly educated (Table 1)
- 47/53 respondents (88.7%) either "strongly" (58.5%) or "somewhat" (30.2%) agreed that receiving an IP to visit GHR was a "good idea"
- 32/53 respondents (60.4%) reported they had 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** (Table 2)
- 22/53 respondents (41.5%) reported that they looked for or would consider **looking for more** health information
- Overall, 43/50 respondents (86.0%) reported that they were **satisfied** with the health information found on GHR, and 40/50 (80.0%) would **recommend the site** to others

### Conclusions:

- Use of a physician-directed IP to visit GHR was well received by pilot study participants at a metabolic clinic
- Respondents expressed a high level of satisfaction with GHR
- 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
  - ▶ prompting further information-seeking behaviors

### References:

1. Ritterband LM, Borowitz S, Cox DJ, et al. Using the Internet to provide information prescriptions. *Pediatrics*. 2005;116(5):e643-47.
2. Siegel ER, Logan RA, Harnsberger RL, et al. Information Rx: Evaluation of a new informatics tool for physicians, patients and libraries. *Information Services & Use*. 2006;16(1):1-10.
3. Tuffrey C, Finlay F. Use of the Internet by parents of paediatric outpatients. *Arch Dis Child*. 2002 Dec;87(6):534-6.
4. Mitchell JA, Fomous C, Fun J. Challenges and strategies of the Genetics Home Reference. *J Med Libr Assoc*. 2006 Jul;94(3):336-42.

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