

## 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:

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 #6, covering the period from 1/16/09 through 4/15/09

6. Submission Date:

April 15, 2009

## NARRATIVE DESCRIPTION

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

The data collection phase of the study was completed on January 15, 2009. The data files were checked for accuracy and corrections made as needed. Drs. Mitchell and Beaudoin invited Dr. Jason Jones (an adjunct faculty member to the Department of Biomedical Informatics with a PhD in statistics) to assist with data analysis activities. Pursuant to University of Utah and HIPAA policies regarding the sharing of personal health information, Dr. Jones signed a Business Associate Agreement with the University to treat all patient data confidentially. As recommended, a de-identified dataset was prepared and shared with Dr. Jones who conducted a preliminary analysis of the data. Dr. Beaudoin and co-authors prepared a poster submission to the American Medical Informatics Association's annual meeting in November 2009 (please see Appendix for poster submission details).

2. Description of Progress toward the Project's Major Objectives:
  - a. Administrative/Planning Activities: Dr. Mitchell requested a no-cost extension which would extend the Period of Performance from April 1, 2009 to November 30, 2009. (Please see Appendix for letter of request to Dr. Robert Logan.) The extension was approved on March 24, 2009 (please see Appendix for letter of approval).
  - b. Collaborations/Partnerships: Ongoing with Dr. Longo and newly established with Dr. Jason Jones (please see executive summary above).
  - 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: Not applicable at this time.
5. Problems/Corrective Actions (including significant changes made in implementation of the project): None to report at this time.
6. Lessons Learned/Significant Feedback: Not applicable at this time.
7. Projected Activities for Next Quarter:
  - (a) Dr. Beaudoin will continue working with Dr. Jones on data analysis activities.

(b) Dr. Beaudoin will draft a manuscript and submit it to Drs. Mitchell, Longo, Jones and Logan, the NNLM and the NLM GHR Team for review and comment.

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 AMIA poster submission, Dr. Mitchell's letter of request for a no-cost extension and the letter of approval from Mr. Navas.

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

Denise E. Beaudoin, MD, MSPH, MS<sup>1</sup>, Nicola Longo, MD, PhD<sup>1</sup>, Robert A. Logan, PhD<sup>2</sup>,  
Jason P. Jones, PhD<sup>1</sup>, Joyce A. Mitchell, PhD<sup>1</sup>

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## Abstract

*The Genetics Home Reference Web site (GHR) offers reliable information about genetic and metabolic conditions. This pilot study assessed reaction of adult patients and parents of children with metabolic conditions to receipt of an 'Information Prescription' (IP) to visit GHR, and perceived usefulness of information found on the site. Most participants (88%) agreed that receiving an IP was a good idea. Retrieved information was useful in key areas. Referral to GHR may enhance medical management.*

## 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> There is evidence that parents are 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 (<http://ghr.nlm.nih.gov>) was developed by the National Library of Medicine to provide consumers and providers with easy to understand, accurate and reliable health information about genetic and metabolic conditions.<sup>4</sup> The objectives of this pilot study were to determine reaction to receipt of an IP directing patients to GHR, and perceived usefulness of retrieved information to adult patients and parents of children with metabolic conditions.

## Methods

Adult patients and parents of children with metabolic conditions seen at the University of Utah Metabolic Service Clinic between April 28 and November 3, 2008 were invited to participate and given an IP to visit GHR. After obtaining informed consent, participants completed an initial 28-item survey to gather demographic data and information about computer access and Internet use. Participants were asked to visit GHR at least once during the six weeks after the clinic visit and received e-mail and letter 'reminders' at three weeks. At six weeks, participants received a second 'reminder' (with the URL, user name and password needed to access a 31-item online survey) asking them

to complete the survey. Key outcome measures included whether use of GHR increased understanding of medical conditions, encouraged communication with providers, or prompted further information seeking behaviors.

## Results

Eighty-two participants were enrolled in the pilot study and completed the initial survey. With the exception of three adult patients, all participants were parents or caregivers. Eighty-eight percent either strongly (59%) or somewhat (29%) agreed that receiving an IP was a good idea. Fifty-three participants (65%) also completed the online survey. Of these, 80% either strongly (45%) or somewhat (35%) agreed the information on GHR added to what physicians told them, and 60% reported an improved understanding of an illness or health condition. Almost all (94%) reported that a high quality source of health information helps them talk to their physicians, and 42% either looked for or would consider seeking additional health information. More than three-quarters of respondents (84%) reported the information found on GHR was somewhat or very helpful, and 80% would recommend the site to others.

## Conclusion

Use of an IP to direct patients to GHR was well received by pilot study participants, and retrieved information was perceived as useful in key areas.

## 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 and 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.

February 23, 2009

Robert A. Logan, PhD  
Office of Communications  
and Public Liaison  
National Library of Medicine  
Building 38, Room 2S22  
8600 Rockville Pike  
Bethesda, MD 20894

Dear Dr. Logan:

We are writing to request a no-cost extension for the N01LM63504, National Network of Libraries of Medicine (NN/LM) Bioinformatics Project. According to Section B of the Agreement between the NN/LM MidContinental Region and the Department of Biomedical Informatics, the project Period of Performance may be extended pending written approval by both parties.

The proposed change would extend the Period of Performance from April 1, 2009 to November 30, 2009. The extension would provide Dr. Beaudoin, a co-investigator in the study, with additional time in which to complete data analysis, prepare a report for distribution to study participants, and disseminate study findings at the meeting of the American Medical Informatics Association in November 2009. Dr. Beaudoin and Dr. Mitchell are also available to travel to the National Library of Medicine to share project results with NLM stakeholders at a mutually convenient time in the future.

Please let us know if you require further information. We would be happy to discuss this request in greater detail with you at your convenience.

Sincerely,



Joyce A. Mitchell, PhD  
Professor and Chair  
Biomedical Informatics

Brent K. Brown  
Director, Office of Sponsored  
Projects

cc: Angela Ruffin, Director, NN/LM  
Claire Hamasu, Associate Director NN/LM-MCR



DEPARTMENT OF HEALTH & HUMAN SERVICES

Public Health Service

National Institutes of Health  
National Library of Medicine  
Bethesda, Maryland 20894

March 24, 2009

University of Utah  
Office of Sponsored Projects,  
AC 218 SOM  
30 N. 1900 East  
Salt Lake City, Utah 84132

Attention: Claire Hamasu, Associate Director

Subject: Contract No. N01-LM-6-3504, Contracting Officer's Authorization (COA) No. 13

Dear Ms. Hamasu:


This COA reflects Contract Modification No. 5, for award of Enhancement No. 2-07-4: "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."

Under the subject COA, the University of Utah is authorized to extend the performance period of Enhancement No. 2-07-4, at no-additional cost to Contract No. N01LM63504.

Enhancement No. / Title	Period of Performance	Amount Not-to-Exceed
Enhancement No. 2-07-4: "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."	10/01/07 – 11/30/09	\$68,820

The total amount and performance period on this COA shall not be exceeded without prior written approval from the Contracting Officer. This authorization does not amend any terms or conditions of the prime contract and is subject to the availability of existing contract funds.

If you have any questions, please contact me at 301-435-4393 or via email at [anavas@nlm.nih.gov](mailto:anavas@nlm.nih.gov).

Sincerely,  
  
Alejandro Navas  
Contracting Officer  
Office of Acquisitions Management  
National Library of Medicine

Cc: Angela Ruffin, Head NN/LM Network Office (via email)  
Claire Hamasu, Interim Associate Director (via email)