

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,
phone 801-581-4080, FAX 801-581-4297

5. Number and Inclusive Dates of Quarterly Report:

Quarterly Report #5, covering the period from 10/16/08 through 1/15/09

6. Submission Date:

January 15, 2009

NARRATIVE DESCRIPTION

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

The patient recruitment phase of the study was completed during this quarter. A total of 82 participants were enrolled in the study. In an effort to enhance the online survey response rate, follow-up efforts were intensified. In addition to routine follow-up procedures, a memo signed by Dr. Longo emphasizing the importance of the study and urging completion of the online survey was also mailed to non-responders along with a reminder letter from Dr. Beaudoin. This change in study protocol required the submission of an amendment to the University of Utah IRB. The study amendment was approved on December 4 and the above mailings were conducted on December 15 and January 2. In addition, follow-up phone calls were made on January 7 and 8. Follow-up activities have now been completed. A total of 53 study participants have submitted an online survey to date, for an overall survey response rate of 64.6%.

2. Description of Progress toward the Project's Major Objectives:
 - a. Administrative/Planning Activities: A study amendment was submitted to the University of Utah IRB on November 19, 2008 and approved on December 4, 2008. (Please see attached IRB notification.)
 - b. Collaborations/Partnerships: Ongoing with Dr. Longo.
 - 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): The response rate for completion of the online survey by study participants was approximately 39% at the time of submission of the October quarterly report. Study investigators discussed several options to enhance the survey response rate and ultimately opted to include a "memo" signed by Dr. Longo along with a reminder letter from Dr. Beaudoin in a special mailing to all non-responders. In order to avoid any perception of coercion, the memo was not addressed to specific individuals but rather to all study participants (please see attached). A study amendment was submitted to the IRB and was approved prior to the mailing.
6. Lessons Learned/Significant Feedback: Not applicable at this time.

7. Projected Activities for Next Quarter:

- (a) Dr. Beaudoin will verify the accuracy of the data collected by the initial (paper) survey.
- (b) Dr. Beaudoin will contact Phill Wolf to arrange receipt of the data collected by the online survey and contact a statistician for assistance with data analysis.
- (c) Dr. Beaudoin will complete data analysis activities and begin drafting a manuscript and summary report and submit the drafts to Drs. Mitchell, Longo 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 IRB amendment approval and memo from Dr. Longo.

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 (Expanded Study, Provider Reminder Memo 11/08) 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 12/4/2008. 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, Provider Memo, 11/08

Surveys, etc.

Screen Shot, Follow-up Survey, page one, 11/06/08

Other Documents

Reminder Letter with Provider Memo, 11/17/08

Study Description, Revised 11/17/08

Follow-up E-mail 11/17/08

Provider Memo, 11/06/08

Date: December 15, 2008

From: Nicola Longo, MD, PhD
Director, Metabolic Clinic
University of Utah
Department of Pediatrics

To: Study Participants

Thank you for agreeing to participate in the study, '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 consumer-friendly Web site, developed by the National Library of Medicine, offers accurate and reliable information about genetic and metabolic conditions.

I encourage you to visit the site to learn more about your/your child's medical condition and, if you have not yet done so, complete the online survey as instructed by the study investigators. Your feedback about the site is very important. By answering the survey questions, study investigators may learn what you like (and may not like) about the Genetics Home Reference Web site, and take steps to improve it.

Thank you very much for your help with this study.