

A Feasibility Study for the Genetic and Rare Diseases Information Center

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May 7, 2004

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INTRODUCTION

The Genetic and Rare Diseases Information Center (GARD), overseen by the National Human Genome Research Institute (NHGRI) and the Office of Rare Diseases (ORD), has been in operation since January 2001. The need for GARD's services originated from the fact that approximately 25 million Americans are affected by more than 6,000 genetic and rare diseases for which reliable information is often difficult to locate. GARD addresses this need by providing free access to accurate, reliable information about genetic and rare diseases. GARD serves to meet the needs of patients, their families, healthcare professionals, biomedical researchers, and the general public by responding to information requests submitted to GARD by email, telephone, TTY, fax, and U.S. mail.

GARD has three functions: (a) respond to individuals' genetic and rare disease inquiries; (b) maintain a database of information, resources, and research on genetic and rare diseases to facilitate responses; and (c) maintain an information technology infrastructure to facilitate responses. Aspen Systems is contracted to provide the services for all three functions.

The goals of GARD are to:

1. Maintain high quality service by ensuring that individuals are satisfied with the responses and the efficiency and utility of the service; and
2. Raise the public's awareness of GARD and expand the use of the service to minorities and underserved populations.

In the time between its inception in January 2001 and March 2004, GARD received 7,541 inquiries. During this time, GARD received an average of 280 inquiries per month or 15 inquiries per business day. Compared to the time period of 2001 through 2003, inquiries to GARD are on the rise in 2004, with an average of 322 inquiries received per month between January and March 2004. Since adding Spanish services in February 2004, GARD has received an average of 17.5 inquiries per business day (February and March), compared to the average of 15 inquiries received per month between 2001 and 2003.

In March 2004, GARD received 414 inquiries. Fifty-seven percent of these inquiries were received by email, 43% were received by phone, and less than 1% were received by fax. Based on an analysis of the inquiries submitted in the first two years of GARD's operation (this is the time period for which data is available), 62% of the inquiries were first-time inquiries and 32% asked about diseases that had been asked about more than once. The top 10 diseases in the repeat inquiry category were requested between 25 and 51 times; however, most of the repeat inquiries (80%) addressed diseases that were requested no more than five times.

The inquiries that GARD receives are categorized into levels, as defined by Aspen Systems and specified below:

- **Level I:** phone responses, NCI referrals, out-of-scopes, student responses, clarifications, and referrals to ORD
- **Level II:** emails for which there is no comprehensive previous reply already developed
- **Standard:** emails from a previously developed comprehensive response
- **Custom:** emails that include resources that are not yet approved or cannot be written using the Standard Response Format, or need an outside expert opinion

Every GARD response is personalized and tailored to the specific needs of the inquirer, and responses for diseases that have already been written about still require considerable development. Even if a response has already been written, it is quite often out of date and a new search in all the databases is required.

GOALS OF THE FEASIBILITY STUDY

NHGRI and the ORD contracted Goodman Research Group, Inc. (GRG) to study the feasibility of conducting an evaluation of users' satisfaction with the GARD service, including an assessment of users' perceptions of the utility of the responses and the overall quality of the service. If an evaluation was determined feasible, GRG would also recommend parameters for the evaluation, supported by the existing knowledge base acquired through an examination of comparable Information Centers' evaluation efforts and a literature review. The specific objectives for this study included:

- Gather and present data about how comparable Information Centers have evaluated their services.
- Summarize the information in such a way as to identify strengths and weaknesses regarding research design, sampling, and data collection strategies.
- Provide a recommendation as to the feasibility of conducting an evaluation for GARD that is informed by the evaluation efforts of comparable Information Centers and a literature review.
- If the study concludes that an evaluation is recommended, propose an evaluation plan with suggested research design, sampling strategies and data collection instruments.

METHOD

GRG began the feasibility study with a literature search to determine how other Information Centers have approached evaluation and to learn from their methods and findings. The literature review also included a review of the Aspen Systems 2003 document, "Evaluation Needs Assessment: Summary Report" which provided information about the types of data previously and currently being collected by GARD.

The second step in the feasibility study was to identify Information Centers comparable to GARD and to invite their participation in an interview about their previous, current, and/or future evaluation activities. In addition to the information generated from the interviews, GRG reviewed supporting documents, including evaluation plans, surveys and executive summaries when available.

INTERVIEW SAMPLE

GRG worked collaboratively with NHGRI and ORD to determine the sample for the interviews. The sampling objective was to identify multiple Information Centers that were comparable to GARD in their mission and services, and who would be able to share (through interviews and document reviews) their knowledge and experience with previous, current, and/or future evaluation efforts.

Several criteria guided the identification of comparable Information Centers. Information Centers were included if they met the majority, but not necessarily all, of the following criteria:

- Serve the general public including patients, families, friends, physicians, and researchers
- Provide information about health, disease, and/or medical topics
- Respond to questions via email, phone, mail, and/or fax
- Prepare personalized responses; does not post answers on forums or as “frequently asked questions”
- Respond to inquiries within a set amount of time
- Disclaimer stating that the service provides general information and resources and not information specific to diagnosis or treatment
- Provide services free of charge

Comparable Information Centers were identified in two ways. One way was with multiple key word searches using an Internet search engine (e.g., key words such as Information Centers, rare diseases, genetic diseases, ask a genetic question). A second way was to identify Institutes within the National Institutes of Health (NIH) that operate Information Centers and/or Information Clearinghouses.

The search process yielded 16 comparable Information Centers (see Table 1). Although we did not identify any Information Centers identical to GARD, all 16 Information Centers met the majority of the stated criteria.

Table 1
Comparable Information Centers

Organization Name	Available methods for contacting
AIDS Info	Email/phone/fax/mail
Alzheimer's Disease Education & Referral Center	Email/phone
American Heart Association	Web submit
CDC National Prevention Information Network	Online Chat/Email/phone/fax/mail
*National Cancer Institute	Live chat/phone/mail
*National Center for Complementary & Alternative Medicine	Email/phone/fax/mail
National Clearinghouse for Alcohol & Drug Information	Web submit
National Eye Institute	Web submit
National Heart, Lung, Blood Institute	Email/phone/fax/mail
*National Institute of Arthritis & Musculoskeletal & Skin Diseases	Email/phone/fax/mail
National Institute of Child Health & Human Development	Email/phone/fax/mail
National Institute on Deafness & Other Communication Disorders	Email/phone/mail
*National Institute of Diabetes & Digestive & Kidney Diseases	Email/Web submit
National Institute of Mental Health	Email/phone/mail
National Institute of Neurological Disorders & Stroke	Mail/phone
National Primary Immunodeficiency Resource Center	Email/Web submit

*** Participated in interview**

METHOD FOR CONTACTING THE INFORMATION CENTERS

The first step in contacting the identified Information Centers was to locate the individual responsible for overseeing evaluation efforts. For all of the Information Centers, GRG began with a phone number, email address, and mailing address leading to an Information Specialist. GRG called the Information Centers with the intent of speaking with an Information Specialist who could then direct us to the Project Officer or other appropriate individual. When it became apparent that we would need to leave messages with an answering service at many of the Information Centers, we proceeded to send introductory emails to the 16 Information Centers.

The email (see Appendix) introduced GRG and provided an overview of the study. The email also included an invitation to participate in an interview with GRG and a request that the email be forwarded to the appropriate person or that the email recipient provide contact information for the appropriate person. A

follow-up email with a similar request was sent to the subset of Information Centers that did not respond within two weeks (n = 8).

INTERVIEW RESPONSE RATE

Of the 16 Information Centers contacted, four participated in an interview, six did not respond to the two invitations to participate, and six declined participation. The six that declined participation did so because they either had not conducted an evaluation or felt that participation was not in the best interest of their Information Center.

As indicated by these numbers, three-quarters of the Information Centers in the sample did not participate. A representative from one of the Information Centers who declined the invitation indicated that he did not wish to participate because the Information Centers are “competing against each other” for funding. This piece of information may offer some explanation as to why 75% of the Information Centers in the sample did not participate in an interview.

GRG kept NHGRI and ORD abreast of the response rate throughout the process of recruiting participants for the interviews and they attempted to secure additional participants through personal communications with the Information Centers. Unfortunately, the efforts did not yield additional participants.

INTERVIEW PROTOCOL

The protocol GRG developed to guide the interviews (see Appendix) addressed the following topics:

- Overview of the Information Center and the services provided
- The Information Center’s evaluation goals and objectives
- The evaluation methods and a summary of findings
- The Information Center’s successes and challenges with evaluation

To supplement information gathered through the interviews and materials provided by the informants (e.g., executive summaries, evaluation plans, surveys), GRG reviewed the Aspen Systems 2003 document, “Evaluation Needs Assessment: Summary Report” to learn about the types of data previously and currently being collected by GARD. This provided important information about GARD’s existing data collection system and the extent to which its infrastructure could be relied upon should an evaluation be recommended.

RESULTS

OVERVIEW OF LITERATURE SEARCH

GRG conducted a literature search to determine the methods and findings of studies with goals comparable to this feasibility study. The literature search produced several comparable studies, most of which assessed user satisfaction and perceptions of quality with library information services.

User surveys are a common way to assess service quality and user satisfaction within the field of information services. The terms service quality and user satisfaction are often used interchangeably, yet there is general consensus that they are unique constructs. According to one set of definitions, “service quality is a cognitively oriented construct that looks overall at factors that shape customer perceptions, and satisfaction is an affective reaction to service encounters” (Hernon, 2002).

In order to assess service quality, many libraries and other Information Centers have used The Gaps Model of Service Quality. Using this model, gaps between users’ expectations about service provision and perceptions about how the service was actually provided are measured using 22 statements related to five dimensions of quality.

For each statement, the user provides two ratings, one reflecting expectations and the other reflecting actual experience. The difference between the two ratings is calculated for each of the 22 statements and then averaged to create a quality score. The Gaps Model of Service Quality is based on research that has demonstrated that the following five dimensions impact users’ perceptions of service quality:

1. Tangibles (the quality of physical facilities, equipment, personnel, and communication material);
2. Reliability (ability to perform the promised service dependably and accurately);
3. Responsiveness (willingness to help users and provide prompt service);
4. Assurance (knowledge and courtesy of employees and their ability to inspire trust and confidence); and
5. Empathy (the caring, individualized attention that is provided to users).

The studies identified in this literature search administered self-report surveys to library users, and in one case, cancer patients receiving health information booklets. The survey response rates, when reported, varied between 30-50%. Within the Library Information Sciences field, a response rate of at least 50% is considered to be credible (Hernon, 2002).

In addition to assessing service quality and user satisfaction, the literature search identified a third assessment dimension - outcomes assessments. Outcomes assessments gather information to determine whether the institution is meeting its educational goals. The focus of outcome assessments is change in users’ behaviors, attitudes, and knowledge after point of contact with the institution and /or service (Hernon, 2002).

One of the studies identified in the literature review was particularly relevant and informative to possible future evaluations of GARD. This study (Butow et al., 1998) investigated factors influencing patient satisfaction with and use of information booklets about cancer. Thirty-six patients reviewed five cancer information booklets on the dimensions of overall satisfaction and usability. Half of the participants received the booklets while receiving chemotherapy and the other half received the booklets just after completing chemotherapy treatment.

Patient satisfaction was measured using six items adapted from a study by Tattersall et al. (1994), including the degree to which the information was readable, provided information about treatment, aided their understanding, helped family or friends, was well presented, and provided them with enough information. Patients rated each of the six items on a scale from 1 to 5, which were then compiled to form a summary satisfaction score with a maximum score of 30.

One of the findings from this study was that patients' satisfaction with the information positively correlated with the readability of the information. As described in Butow et al. (1998), many existing information services require grade 12 or higher reading skills whereas statistics show that 36-40% of the American population can only read at or below the 4th grade level and 77% read below the grade 9 level.

A second major finding from this study concerned the timing of the information provision. The study found that patients have difficulty recalling information provided near the time of their initial consultation and/or treatment. The effect of timing on recall has been documented in other studies. For example, in a study examining the effects of information given to patients either before or after their oncology consultation, Dunn et al. (1993) found that information was more beneficial if provided to patients prior to the initial consultation. Another study by Hughes (1993) found that recall of information presented to breast cancer patients at the time of diagnosis was extremely poor. It was suggested that providing information in small increments may allow the patient to adjust to diagnosis and treatment.

FINDINGS FROM THE ASPEN SYSTEMS 2003 EVALUATION NEEDS ASSESSMENT

Aspen Systems Corporation drafted an evaluation needs assessment for GARD in July 2003. The purpose of the needs assessment was to identify gaps in GARD's current data collection activities, and to make recommendations for a subsequent formal evaluation of GARD. It was determined that the needs assessment as well as a possible evaluation should be conducted from outside Aspen Systems.

The findings from the needs assessment indicated that several pieces of information are currently being documented in an Inquiry Tracking Log (ITL) system at GARD. The types of information currently being documented in the ITL includes, but is not limited to, the number of clients served, the relative labor for each response, the speed of service, and the method used to contact GARD. (See the attached Needs Assessment Report for complete information).

The needs assessment concluded that while GARD currently has several quality control policies and procedures in place, GARD does not actively collect data on user satisfaction or demographics. Currently, Information Specialists assess users' demographics through observed characteristics, such as the sound of a caller's voice to determine gender, or the Information Specialist extrapolates demographic information from the contents of the inquiry. GARD collects some indication of users satisfaction from comments and letters of appreciation sent to GARD.

The needs assessment identified three evaluation questions for GARD to focus on: 1) who is GARD reaching, and how; 2) does GARD provide services that people want and need; and 3) how can GARD improve?

The needs assessment recommended the following data be collected in a formal evaluation of GARD:

- User demographics (gender, age, race/ethnicity, ZIP code, education level, income, profession, and relationship to the information)
- Whether responses were viewed as reliable and current
- Whether novel or redundant information was provided
- What was most and least useful about the response
- Whether the content was tailored to the question
- Whether the response was timely, clear and concise
- What the consumer intended to do with the information
- Suggestions for improvement and other services

In sum, the needs assessment recommended that GARD pursue a formal evaluation to address these questions, and that a formal evaluation of users' demographics and satisfaction would help NHGRI and ORD to refine GARD's services so that they can address the needs of users and target outreach efforts to those who are currently being underserved.

CASE EXAMPLES OF INFORMATION CENTERS' EVALUATION APPROACHES

GRG's interviews with representatives from comparable Information Centers, as well as GRG's review of supplementary materials (e.g., executive summaries, evaluation plans, and surveys), indicated that user satisfaction-focused evaluations are the most common type of evaluation currently being conducted. In very few cases, evaluations of Information Centers have assessed the longer-term outcomes of information provision on users' knowledge and behavioral intentions.

That the majority of evaluations are focused on user satisfaction is likely due to the fact that, compared to outcome evaluations, user satisfaction evaluations are less expensive, less burdensome to users and staff, and can be completed in a shorter amount of time. The relative ease of completing a user satisfaction evaluation is also supported by the introduction of a generic clearance allowance in 2001, whereby the Online Information Branch (OLIB) received a blanket clearance from the Office of Management and Budget (OMB) for the NIH to perform user satisfaction surveys on all of its Web sites. This expedited process is expected to take 4-6 weeks from the time OLIB receives the request to the time it receives clearance, as opposed to the many months it can take to receive the non-generic OMB clearance.

Relatively few evaluations of Information Centers are focused on information use and the longer-term outcomes of information provision on knowledge, attitudes, and behavior. Besides being more costly and taking longer to complete,

Information Centers need to realistically consider the outcomes that information provision can be expected to lead to.

In order to justify the costs and efforts necessary to undertake evaluations focused on information use and long-term outcomes, the Information Center must first explicate the types of information use that can be expected and the specific ways in which information provision will contribute to changes in knowledge, attitudes, and behaviors. This explication of information use and possible impact can be accomplished with the creation of a logic map.

The following case examples, synthesized from the interviews and document reviews, illustrate the approaches Information Centers have taken to evaluate their services. The case examples represent a range of evaluations from those that focus on user satisfaction to those assessing longer-term outcomes for users' knowledge and behavior. The case examples also vary with regard to the size and scope of the Information Centers, with the larger and more established Information Centers implementing more comprehensive evaluation plans.

Case 1: National Institute of Diabetes and Digestive and Kidney Diseases

The National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) oversees three Information Clearinghouses: (1) The National Diabetes Information Clearinghouse; (2) The National Digestive Diseases Information Clearinghouse; and (3) The Kidney and Urologic Diseases Information Clearinghouse. The three Information Clearinghouses serve different populations but operate with a similar mission: to increase knowledge and understanding about diabetes, digestive, and kidney diseases among patients, health care professionals, and the general public through the public dissemination of materials, publications, and resources.

The Clearinghouses offer several services, including responding to inquiries for education materials and statistical data; dissemination of publications; referrals to health professionals through the National Library of Medicine's *MEDLINEplus*; and access to the Combined Health Information Database (CHID), a database of health education materials.

Inquiries are submitted to the Clearinghouses by phone, email, fax and mail. As an example of the volume of inquiries received, the Kidney and Urologic Diseases Information Center receives, on average, 3,000 inquiries per month. Telephone inquiries account for approximately one third of inquiries. Email inquiries are a second common method for contacting the Information Clearinghouse. The informant did not know the percentage of inquiries received for each method of contact.

The NIDDK is currently conducting a process evaluation and a user satisfaction evaluation of its three Clearinghouses. The evaluations are conducted entirely in-house, with no assistance from an external evaluator. Both types of evaluation have been in existence for several months and data will be collected on an ongoing basis.

The process evaluation is an evaluation of how many people are being served by the Clearinghouses and the types of information being requested. This information is documented by the Information Specialists every time an inquiry is submitted. Quarterly reports summarizing this information are distributed to staff.

The Clearinghouses are driven by their mission to disseminate information to the public rather than impact individuals' behaviors (which is the responsibility of the education division). As such, the evaluation is focused on user satisfaction rather than an assessment of knowledge acquisition or behavioral change.

All three Clearinghouses are administering a 12-item survey to individuals submitting inquiries. The survey consists of closed-response questions asking the respondent to share the following types of information:

- The number of times they have visited the Clearinghouse
- How they heard of the Clearinghouse
- Individuals' relationship to the inquiry (e.g., patient, family)
- The products and services received from the Clearinghouse
- Perceptions of the quality of the information received
- A description of what was most helpful about the information
- Overall satisfaction with the Clearinghouse

The survey is being administered on an ongoing basis, and every inquirer is asked to participate. The user satisfaction survey is being administered online and by telephone. When individuals submit an inquiry by email, the response that they receive includes a link to the online survey. When individuals call the Clearinghouse with an inquiry, they are asked whether they are willing to have an Information Specialist call them at a later date to ask them about their satisfaction with the requested information. If the caller indicates a willingness to be called, the Information Specialist calls the inquirer 2-3 weeks later.

The Clearinghouses do not have target response rates that they are seeking to obtain, and the informant did not have knowledge of how many responses had been collected to date. The informant indicated that they have not had difficulty getting individuals to participate, including those who are called at a later date. Information Specialists perform all the recruiting and administer the telephone surveys themselves.

The Clearinghouses have received full OMB clearance to conduct the evaluation. The informant indicated that the Clearinghouses could have applied for a generic clearance for the online survey but had already prepared the full clearance application.

In addition to conducting the process and user satisfaction evaluations, the Clearinghouses have also conducted formative evaluations for a few of their new products. At national conferences they have asked attendees to participate in usability tests of the Web site, and they have contacted support groups to review relevant products that are being developed.

In sum, the informant indicated that the findings from the evaluation have been useful and have led to several changes at the Clearinghouses including making online ordering available, adding Spanish translations, and creating easier to read booklets.

Case 2: National Institute of Arthritis & Musculoskeletal & Skin Diseases

The National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) Information Clearinghouse serves multiple functions. First and foremost, the Clearinghouse responds to inquiries that are received via email, phone, and fax, with email being the most frequent contact medium. Second, the Clearinghouse oversees and coordinates the printing, publication, and dissemination of brochures about arthritis and musculoskeletal and skin diseases. Third, the Clearinghouse operates a patient liaison and referral program.

The NIAMS Information Clearinghouse is similar to GARD in that the inquiry response services are contracted to an external agency, the inquiries are responded to within a specific amount of time, the responses range from standard to complex, and the primary audience includes patients, family, and healthcare professionals. The Clearinghouse currently employs six Information Specialists, however they do not work exclusively on responding to inquiries; they also serve the functions related to patient liaisons and development of new materials.

The NIAMS Information Clearinghouse was externally evaluated in 2002. The evaluation focused on users' satisfaction with the inquiry and response services and the dissemination of materials. The purpose of the evaluation was to assess whether people perceive the staff and service to be friendly and helpful, and how the Clearinghouse could improve its services.

The evaluation took place over the course of three months and included user satisfaction surveys and focus groups. A sample of users was surveyed via paper, online, and telephone surveys. In total, the Clearinghouse collected approximately 300-500 survey responses over a three-month period, resulting in approximately 10-15% of users in the three-month period completing a survey.

If an individual submitted an email inquiry, the response included a link to an online survey. If an individual made an inquiry by telephone, s/he was asked to participate in a telephone survey at the end of the conversation. Users were also given the option of receiving a paper version of the survey and returning it by mail.

The survey consisted of five questions that asked about the helpfulness of the Clearinghouse, users' satisfaction with the services, the methods used to contact the Clearinghouse, the reasons for contacting the Clearinghouse, the types of information received from the Clearinghouse, and the value of the Clearinghouse materials in terms of content and presentation.

An external evaluator also conducted two focus groups composed of eight Clearinghouse users each. All participants had diseases and conditions addressed

by NIAMS. After telephone screening and selection from an existing database of users, each focus group member was asked to contact the Clearinghouse by an assigned method (e.g., telephone inquiry or email inquiry) and make a request for information related to a personal health issue. The focus groups addressed the following topics: 1) method used to contact the Clearinghouse; 2) satisfaction with the process of receiving information; 3) the value of the publications; and 4) the value of the NIAMS Web site.

Overall, the evaluation findings were very positive. Participants indicated that the Clearinghouse staff was friendly, helpful, and knowledgeable, and the email inquiries were responded to promptly. In contrast, the turnaround time for mailed inquiries was considered too long. In response to this evaluation finding, the Clearinghouse instituted a policy of notifying the public how long they can expect it to take to receive a response. It was also recommended that the telephone number always include the numbers in addition to letters. For example, (301) 495-4484 in addition to (877) 22-NIAMS.

The informant commented that the focus groups were helpful (in fact more helpful than the survey) because they provided useful information about how to improve the publications. For instance, the focus groups found that people would like to see more graphics in publications and that the reproduced brochures were difficult to read. In response, the Clearinghouse now uses a master copy rather than duplicates to make copies. The informant said that this is a simple idea but that it makes a difference. Without the focus groups they would not have known this.

Overall, the evaluation met the Clearinghouse's needs. When asked what NIAMS would do differently if they were to conduct another evaluation, the informant indicated that she would focus the survey questions on how people *use* the information received. She described that the Clearinghouse is pressured to show that information dissemination leads to certain outcomes.

The informant also reported that the Clearinghouse obtained full OMB clearance for this evaluation and that obtaining the clearance was a lengthy process. With regard to funding the evaluation, NIAMS used money from a specific fund set aside within NIH for evaluation.

Case 3: National Center for Complementary and Alternative Medicine

The National Center for Complementary and Alternative Medicine (NCCAM) operates a Clearinghouse for information on complementary and alternative medicine. The Clearinghouse responds to approximately 1,000 requests per month that are received by phone, email, and fax. The most frequent methods for contacting the Clearinghouse are by telephone (62% of all inquiries) and email (23% of all inquiries). The Clearinghouse also operates a Web site and produces a quarterly newsletter. The Clearinghouse currently funds 5 FTE Information Specialists who are externally contracted.

NCCAM is currently conducting its first evaluation, and it is focused on assessing users' satisfaction with the Clearinghouse. The evaluation is scheduled

to take six months to complete, and although the Clearinghouse is conducting the evaluation primarily internally, it does consult with an external evaluator from time to time. According to the evaluation plan, the evaluation goals are to assess the extent to which the public is aware of the Clearinghouse, and to evaluate how satisfied users are with the information provided by the Clearinghouse. The informant described the evaluation as being process-oriented and not outcome-oriented.

The Clearinghouse is administering user satisfaction surveys to individuals who submit questions to the Clearinghouse via telephone and email. The Clearinghouse will eventually evaluate users' satisfaction with the Web site and the quarterly newsletter. The same survey will be used for all components so that comparisons can be made across the methods of contact.

When an individual contacts the Clearinghouse by telephone, a prompt is displayed on the Information Specialist's screen, and the Information Specialist asks the caller if s/he would be willing to complete a brief (3 minutes) telephone survey at that time. For individuals who submit questions via email, a link to the online survey is included in all responses.

NCCAM is attempting to survey approximately 10% of its users. In total, the target number for completed surveys is 1,000 respondents (500 online surveys and 500 telephone surveys), equal to the average number of inquiries received by the Clearinghouse each month. The target number of completed online surveys was achieved within 3-4 months. Achieving the target number of completed telephone surveys is proving more difficult to achieve. The informant did not have access to current numbers. The evaluation is scheduled to continue through April 2004.

The survey consists of the following questions:

- How did you first find the NCCAM Web site? (Select from a list)
- What type of information were you looking for? (Select from a list)
- Did you research your question on the NCCAM Web site before sending an email? (Yes/No)
- Did the response arrive within 5 business days? (Agreement rating on a 1-5 scale)
- Did the response adequately answer the question? (Agreement rating on a 1-5 scale)
- Did the response provide helpful resource links? (Agreement rating on a 1-5 scale)
- Overall, were you satisfied with the response? (Agreement rating on a 1-5 scale)
- Do you have any suggestions for improving the responses? (Yes/No/List)
- What is your relationship to the inquiry (e.g., patient, family)? (Select from a list)
- What is your age? (Select from a list)
- What is your gender? (Female/Male)
- What is your race and ethnicity? (Select from a list)
- Provide zip code

According to the statement provided on the online version of the survey, “public reporting burden for this collection of information is estimated to average 3 minutes per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information.”

The Clearinghouse has attempted to coordinate the various evaluation activities (survey of inquiry/response service, surveys about the Web site, and surveys about the quarterly newsletter) with the timeframe needed to obtain OMB clearance. As they receive OMB clearances, they phase in the pieces of the evaluation. When asked if there were lessons learned from the OMB clearance process, the informant explained that it is a detailed process that has taken twice the amount of time that they anticipated.

With regard to funding this evaluation, the informant indicated that the funding comes from NCCAM’s current contracts. This has been made possible because NCCAM is keeping the costs at a minimum by conducting portions of the evaluation internally, and they are not using expensive features such as random digital dialing and fees associated with buying phone numbers and addresses.

Case 4: Cancer Information Service

The Cancer Information Service (CIS) is a program of the National Cancer Institute (NCI) that provides up to date and accurate cancer information to patients, their families, the public, and health professionals. Through a network of regional offices, CIS serves people in the United States, Puerto Rico, the U.S. Virgin Islands, and the Pacific Islands.

CIS consists of three programs briefly described below:

- The **Information Service** provides personalized cancer information in English and Spanish through a toll-free number as well as information dissemination on smoking cessation, recorded information, a TTY line for the deaf and hard of hearing, a Web-based instant messaging service called *LiveHelp*, and the CIS web site.
- The **Partnership Program** collaborates with partner organizations regionally and nationally to reach minority and medically underserved populations and populations with limited access to cancer information.
- The **Research Initiative** collaborates with researchers external to NCI to conduct cancer communication research.

The CIS has a long history of evaluation, with user surveys conducted in 1976, 1984, and 1996. The planning for CIS’ current evaluation began in early 2000 with the formation of an internal CIS evaluation team composed of a Project Officer for Evaluation and an Evaluation Specialist. The team convened planning meetings where program goals were defined, stakeholder involvement was discussed, and an evaluation work plan was devised. The team also worked with an external evaluator to further develop the comprehensive evaluation plan that

resulted in logic models, evaluation questions, and process and impact measures for each program component.

The Information Service program within CIS provides personalized, confidential responses to questions submitted via a toll-free telephone number (a routing system directs the caller to the appropriate regional office), a “Quit” line that provides telephone advice, “live help” with an instant messaging service, and email. Through these different mediums, CIS users receive answers to their questions about cancer, including information about prevention, diagnosis, and treatment.

The toll free number is the most frequently used method for contacting the Information Service program, with an average of 15,000 telephone calls received per month. The Information Service receives an average of 4,500 emails per year. The overall volume of inquiries that the Information Service receives has decreased in recent years. The informant believed this was likely due to the public’s increased use of the Internet to locate resources and because the budget for CIS promotion activities was significantly decreased.

The Information Service evaluation plan includes both process and impact objectives and measures. The process and impact objectives were defined through the development of a logic model. The logic model outlined the specific mechanisms through which the service was expected to benefit the public, and it provided a foundation for identifying appropriate measures and target performance indicators.

The process objectives focus on insuring that the Information Service is operating as intended, that the public has access to the Information Service, and that users of the service are satisfied. The impact objectives focus on assessing how the Information Service affects users’ knowledge, awareness, attitudes and behavioral intentions.

The logic model predicts that as users’ knowledge, awareness, and self-efficacy increases, their intention to engage in healthful behaviors will also increase and their communication with health professionals will improve. The specific impact questions are:

- Does use of the Information Service increase users’ knowledge and awareness about cancer topics and ability to acquire information about the subject of interaction?
- Does use of the Information Service have a positive impact on users’ attitudes related to cancer?
- Does the use of the Information Service increase users’ self-efficacy with regard to communicating with health professionals about cancer, personal health promotion, and cancer-related decision-making?

The process and impact objectives are measured using a combination of existing and new data collection tools. As part of its ongoing operations, the Information Service uses an electronic contact record form (ECRF) that collects information on 25 variables including type of user, subject of interaction, and user demographics. The CIS has OMB approval to collect demographics on a certain

percentage of callers and ZIP code information from all callers. ECRF data are exported to a data management contractor who generates monthly ECRF reports.

As part of its current evaluation, the CIS is surveying a random sample of callers, whereby 50% of callers are randomly selected for recruitment. For now, the sample is derived only from the toll-free telephone callers. Strategies for involving participants from the Spanish call centers, the web chat service, and the CIS Web site are expected to be incorporated at a later date.

When a caller is randomly selected, a recruiting screen instructs the Information Specialist to request the callers' demographics. If the individual has never used the service before, they are also asked if they would be willing to participate in a telephone survey three weeks later. At this time, data collection is still underway, and the response rate is nearing 65% of the targeted 2,500. In order to increase the number of survey respondents, the CIS is revising the script that Information Specialists use to recruit participants.

The survey assesses both process and impact indicators. Process indicators include callers' perceptions of the Information Specialists' knowledge, callers' trust in the information provided, and the likelihood of recommending the service to others. Impact indicators include users' knowledge, attitudes, self-efficacy, and behavioral intentions about cancer-related topics.

Performance targets for the process indicators were set based on previous evaluation findings. Since this was the first time the Information Service would assess impact, performance targets for the impact objectives were not set in advance.

The informant expressed that with earlier evaluations, such as one conducted in 1996, the CIS backed into the evaluation based on the data that was already being collected. The CIS adopted a new approach for this evaluation by first determining what questions they wanted answered, looking to see what data they were already collecting, and identifying the types of measures that would need to be developed.

The informant stressed the importance of creating a logic map when assessing impact. Further, the informant advised deciding at the start what you are willing to take responsibility for and ensuring buy-in from all the constituents (e.g, staff, funding agencies, etc.). According to the informant, "evaluation provides an excellent way to learn about the organization but only if you get the objectives to a measurable place. What you measure matters."

The informant was asked to share what she has learned about the process involved with securing OMB clearance. The informant's response was that OMB is a challenging process and she advised that one plan far in advance, even when applying for the generic clearance.

CIS funds this evaluation within their existing budget. The informant was hired specifically to oversee the evaluation and has full support of her supervisor. She is currently applying for specially allocated money within NIH to support the evaluation.

Finally, the informant was asked what kind of training was provided to the Information Specialists for this evaluation and she said that the Information Specialists received training related to recruiting strategies. The informant indicated that it is difficult to get staff motivated to recruit. CIS often receives feedback that participants appreciate being asked to share their opinions. This observation supports findings from GRG's literature review in that "the survey...is a very important communication to customers. It makes certain implied promises about the organization's interest in and responsiveness to its customers" (T. Vavra as quoted in Hernon, 2002). As such, CIS makes a point of sharing this positive feedback with the Information Specialists on an ongoing basis in order to motivate their recruiting efforts.

CONCLUSIONS

As described in the case examples, several Clearinghouses and Information Centers within the National Institutes of Health have already or are currently conducting evaluations. GRG's analysis of the Information Centers' approaches to evaluation lead to the following conclusions:

- The Information Centers reviewed in this feasibility study were determined to be comparable to GARD on several dimensions, however no one Information Center is exactly like GARD. GARD is providing a very unique service to the public in that the population served is faced with a broad scope of genetic and rare diseases, and the information that is being provided is necessarily specialized in a way that differentiates it from other Information Centers.
- The most common type of evaluation currently being conducted is a user satisfaction evaluation with samples that approximate 10% of the user base. The primary measures used in these evaluations are online and telephone surveys comprised of 10-15 closed-response items. The surveys take approximately three to five minutes to complete, have received generic and full OMB clearances, and focus on user demographics, how the user located the service, and whether the user was satisfied with the response and service.
- A second type of evaluation that surfaced in this study was one focused on users' use of the information, with efforts being made to measure the impact of information acquisition on users' attitudes, knowledge, and behavior. This type of evaluation is conducted far less often than user satisfaction-focused evaluations.
- Although the user satisfaction-focused evaluations are common and more easily accomplished than outcome evaluations focused on information use and behavior change, there appears to be a general press for the Information Centers to move beyond assessments of user satisfaction and towards outcomes assessments.
- The Information Center in this sample that was conducting an outcome evaluation took several steps to prepare itself for an evaluation of this

scope and size. In addition to having a long history of evaluation and serving large numbers of people, the Information Center created an internal evaluation team and spent considerable time and effort developing a logic map complete with inputs, outputs, objectives, and indicators for short- and long-term success.

RECOMMENDATION

Based on the above conclusions, GRG recommends that NHGRI and ORD proceed with an evaluation that first assesses the population being served, users' satisfaction with the service being provided, and how users intend to use the information received. After learning about who is being served by GARD and the extent to which GARD is meeting the needs of its target audience, GRG recommends that NHGRI and ORD proceed with an evaluation of the extent to which the information is being used. Ultimately, this is the type of data (information use) that will meaningfully communicate the impact of GARD's services.

NHGRI and ORD Program Officers have communicated that they are interested in evaluating users' satisfaction with GARD. GRG believes that it will benefit GARD to also evaluate whether and how individuals are using the information they receive from GARD. Like other Information Centers, GARD will be increasingly expected to prove its value and worth in return for the funding that maintains and promotes the service. User satisfaction surveys will generate findings that tell GARD the extent to which the public views the service as valuable. Although this information is important and meaningful, it will not provide the type of evidence (impact and outcome-focused) needed for the realities of this political and budgetary era.

GRG also recommends that GARD work with an evaluator to develop a logic map if they decide to evaluate whether and how individuals use the information they receive from GARD.

The process of creating a logic map combined with the findings from a user satisfaction survey will likely point to new areas of development for GARD's services. If GARD decides to expand or revise its services during the evaluation period, GRG recommends the addition of focus groups to the evaluation design to gather audience feedback about new GARD services.

RECOMMENDED EVALUATION PLAN

Based on the findings from the feasibility study, GRG proposes the following evaluation plan. In making this proposal, GRG was sensitive to the demands of the evaluation design on the users of GARD, and wherever possible, chose the least burdensome approach.

Evaluation Goals

The purpose of the proposed evaluation is to provide a description of the audience being served by the GARD Information Center, users' satisfaction with the services received, and users' subsequent use of the information received. Specifically, the goals of the evaluation will be to:

- Describe who is being served by GARD,
- Identify the ways in which individuals locate GARD,
- Assess users' satisfaction with GARD in terms of the quality and accuracy of responses and interactions, and the extent to which the service fills a need,
- Identify the audience's intended use(s) for the information received, and
- Assess the audience's subsequent use and application of the information received.

Evaluation Design

GRG proposes a two-phase evaluation design that will use the survey method to address the evaluation goals.

Sample Selection for Phase I: User Satisfaction Survey

Individuals will be recruited to participate in Phase I of the evaluation when they submit an inquiry to GARD via telephone, email, or mail. All responses that GARD delivers in a three-month period will include either the Web address for an online user satisfaction survey or a paper version of the survey with a postage-paid return envelope.

When individuals call GARD, the Information Specialist will ask the inquirer, at the end of the exchange, if they would be willing to complete a brief user-satisfaction survey. If the individual indicates a willingness to participate, the Information Specialist will ask the respondent for either an email address to which a URL to the Web survey can be sent or a mailing address to which the survey and a postage-paid return envelope can be sent. Inquiries that are made by email will include a URL to the Web survey.

GRG's review of other Information Centers' evaluation parameters indicated that the Information Centers interviewed for this study aim to survey approximately 10-15% of their users. Compared to some standards, this is a low target response rate. Because GARD receives fewer inquiries than the Information Centers interviewed for this study, GRG recommends that GARD attempt to survey 50% of its inquirers over a three-month period. In March 2004, GARD received 414 inquiries. If this volume continued over three months, the total number of inquiries would be 1,242. Successfully surveying 50% of those inquirers would result in approximately 600 survey respondents.

Sample Selection for Phase II: Information Use Survey

At the end of the user satisfaction survey, participants will be asked if they are willing to complete a follow-up survey two to three weeks later. GRG recommends targeting a 50% response rate for this follow-up survey. A 50% response rate on the follow-up survey would result in approximately 300 follow-up respondents. As with the user satisfaction survey, participants would have the choice of completing either a Web survey or a paper version of the survey.

Data Collection

Phase I: User Satisfaction Survey

GRG will draw on its own expertise and review of existing surveys administered by comparable Information Centers to develop the user satisfaction survey. The user satisfaction survey will gather information pertaining to the participants' demographics, how they located GARD, their reason for contacting GARD, their satisfaction with the service they received, and how they intend to use the information they received. The user satisfaction survey will primarily consist of closed-response questions, with a minimal number of open-ended questions. The survey will be expected to take five minutes to complete to insure that the survey is not burdensome to the public.

Phase II: Information Use Survey

The purpose for the follow-up survey is to assess whether and how participants used the information they received a few weeks earlier, and for those who follow through with GARD's suggested resources, whether they were useful and beneficial.

As with the user satisfaction survey, the follow-up survey will primarily consist of closed-response questions, with a minimal number of open-ended questions. The survey will be expected to take five minutes to complete to insure that the survey is not burdensome to the public.

Focus Groups for New Services

If appropriate, GRG will conduct four focus groups to discuss new and revised services in development at GARD. The focus groups will include a national sample of eight to ten participants each. The focus groups will be led by GRG researchers and would last approximately two hours each. A focus group protocol developed by GRG will guide the group discussions and focus on soliciting participants' opinions and feedback regarding the value and usefulness of new services from GARD. Participants will be recruited from GARD's database (developed, in part, from the Phase I survey) of users, and participants will receive a stipend in return for participation.

Considerations

- GRG recommends the administration of online and paper surveys as opposed to telephone surveys because the costs and time required to conduct telephone surveys are far greater than the costs and time associated with online and paper surveys.
- GRG does not advise having the Information Specialists conduct telephone surveys at the end of telephone inquiries. Not only are the Information Specialists not trained to collect evaluation data, such data collection efforts would be burdensome to the staff.
- GRG recommends the survey method, as opposed to focus groups, to assess user satisfaction and information use. The survey is an appropriate method for documenting individuals' opinions and experiences, and can be designed to be minimally burdensome. Focus groups are much more suited to soliciting a target audience's reactions to a stimulus, such as a new product, and the ensuing dialogue is useful for brainstorming new ideas and suggestions for improvement. Focus groups are more labor intensive and expensive than surveys and should be administered when the objective is to gather rich, in-depth information from a small number of people, as opposed to sampling the opinions of a broad range of users.
- The period of time needed to complete the evaluation activities will be dependent upon the receipt of OMB clearances. It is estimated that it will be relatively quick and easy to get a generic OMB clearance for the online version of the user satisfaction survey but likely more difficult and time consuming to receive OMB clearance for the paper version of the user satisfaction survey, the Phase II follow-up survey, and the focus groups, should they be included. If the full OMB clearance is not obtained by the time that the follow-up surveys in Phase II are to be administered, a new sample would probably need to be recruited for Phase II.
- As the evaluation proceeds from Phase I to Phase II, it will be important for GARD to work collaboratively with the evaluator to develop a logic map that explicates the expected indicators of success pertaining to information use.

Data Analysis and Deliverables

GRG will analyze quantitative and qualitative data for all measures described. Descriptive statistics will be used to describe the users of GARD's services, how users locate GARD, users' satisfaction with the service, users' intentions to use the information, and finally, follow-up information as to whether and how the information was used. GRG will provide NHGRI and ORD with a final report of the findings and recommendations at the conclusion of the evaluation.

Timeline of Evaluation Activities

July 2004	Finalize evaluation plan
Aug – Sept 2004	Develop Phase I surveys (user satisfaction) Create logic map with client Develop Phase II (information use surveys) NHGRI and ORD submit materials for generic and full OMB clearance
Oct – Dec 2004	Wait to receive generic and full OMB clearance
Jan – April 2005	Administer Phase I surveys for 3-month period Revise Phase II survey based on initial Phase I data Administer Phase II surveys 2-3 weeks after Phase I survey administration
May – June 2005	Potentially conduct focus groups Analyze Phase I and II survey data Analyze focus group data
July 2005	Write report
August 2005	Submit final report

Budget

The budget detailed below separates the cost for the Phase I (user satisfaction) and Phase II (information use) evaluation from the cost of the focus groups given that the focus groups are recommended only if GARD expects to develop and/or expand services.

Phase I and Phase II Evaluation

Personnel (includes fringe)	\$30,156
Other direct costs (e.g., phone, post, photocopy)	1,209
Spanish translation	1,200
Total direct costs	32,565
Indirect	16,283
TOTAL	\$48,848

Focus Groups Only

Four focus groups with 10 people each to be held in four national locations.

Personnel (includes fringe)	\$14,331
Other direct costs (e.g., stipends, phone)	3,450
Focus group facility	3,750
Travel costs	4,770
Total direct costs	26,301
Indirect	13,151
TOTAL	\$39,452

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APPENDIX

INVITATION TO PARTICIPATE

Dear Information Specialist,

My name is Jennifer Beck, and I am a research associate with Goodman Research Group, Inc. (GRG), a research firm in Cambridge, MA specializing in the evaluation of educational programs, services, and materials. GRG is assisting the National Human Genome Research Institute (NHGRI) and the Office of Rare Diseases (ORD) staff in determining the feasibility of conducting an outcome evaluation of the Genetic and Rare Disease (GARD) Information Center.

As part of our feasibility study, we are interested in learning how similar organizations have evaluated their information services. GARD is interested in learning from others as they prepare for the possibility of conducting an evaluation. GRG identified your services in our search for comparable organizations, and I am interested in learning whether or not your organization has conducted an evaluation of the information services provided.

At this time, I am seeking contact information for an individual in your organization who has knowledge of past, current, or prospective evaluations of your organization's information services. Once I have located the appropriate contact, I would like to request his/her participation in a brief telephone interview.

Thank you in advance for your cooperation. The information you provide will contribute to our understanding of the feasibility of conducting an evaluation of health and medical-related Information Centers.

Sincerely,

Jennifer Beck, Ph.D.
Research Associate

INTERVIEW PROTOCOL

INTERVIEWER INTRODUCTION

- Interviewers' name and affiliation
- Describe purpose of the call
- Do you have 20 minutes to answer a few questions now?
- If yes, continue with questions.
- If no, schedule a time to call again.

ABOUT THE INFORMATION CENTER

- Ask for a description of the Information Center and the services provided.
- Is any of the work (e.g., the call center) subcontracted to another organization?
- Does your organization respond to individuals' requests for information and resources? If yes, continue.
 - If no, ask for a description of services provided and determine comparability.
- What topics do you respond to?
- Who is your primary audience?
- In what format can questions be submitted (e.g., phone, mail, email, fax)?
- In what forms are responses provided? How is this determined? What does it depend on?
- In what time frame does the center respond to questions?
- Are all questions answered?
 - If no, what determines (e.g., too many q's, not qualified to answer) and do you refer to another organization?
- Do you provide personalized responses? (Defined to mean custom responses that are not easily answered in the public domain. For GARD, the project officer reviews.)
- Do you employ information specialists?
 - If yes, how many?
 - If yes, what are their backgrounds?
- How is the service funded?
- Do you attach a disclaimer to your response?
 - If yes, what is the disclaimer?
 - If yes, all of the time, some of the time, what does it depend on?

PREVIOUS, CURRENT, AND FUTURE EVALUATIONS

- Have your services been evaluated in any way? (For example, determining your audience, audience needs and satisfaction, types of inquiries, quality and content of responses.)
 - If yes, previously or currently?
 - If yes, formally (paid) or informally (unpaid)?
- How many times have the services been evaluated?
- When was the most recently completed evaluation(s) conducted?
- Was it an external or internal evaluation (internal refers to someone within the org.; external refers to a hired outside consultant)?
- If internal, who conducted the evaluation?

- What time period did the evaluation cover?
- Why was the evaluation conducted? For what purposes?
- Can you describe the process involved in gaining OMB clearance?
- What questions did the evaluation seek to address?
- What will indicate success for your organization? (e.g., goals, objectives, benchmarks)
- What methods were used to address the evaluation questions? (e.g., surveys, interviews)
- Which, if any, of the methods were particularly successful or challenging?
- Who provided information for the evaluation?
- Staff and/or audience and how?
- What, if any, were the particular challenges or obstacles in completing the evaluation?
 - If yes, describe.
 - If yes, how were they addressed?
- How were the evaluation findings presented to you? (e.g., verbally, presentation, written report).
- If written report exists, ask if there is an executive summary available to the public and if we could have a copy.
- What were the evaluation findings?
- Did the evaluation meet your organization's needs?
- What did you do with the information you received from the evaluation?
- What changes, if any, were made to the services as a result of the evaluation?
- Where did the funds for this evaluation come from and can you provide an approximation of the budget allowed for the evaluation?
- Overall, did you find the evaluation to be useful and worth the effort and money?
- Will you conduct another evaluation in the future?
- If you were to have another evaluation completed, what would you do differently?
- What would you do the same?
- Do you know of any similar services that have had evaluations conducted? If yes, who?
- Did you get any evaluation ideas from them? Describe.

END. Thank you for participating. Request email address in case we have follow-up questions. Provide our contact information in case they have follow-up questions.