Final Report

Evaluation of the Information Clearinghouse for the National Institute of Arthritis and Musculoskeletal and Skin Diseases

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Submitted by:
Amy Thurston
Cynthia Mariel
Marguerite Autry
Richard Horst
UserWorks, Inc.
1738 Elton Road, Suite 138
Silver Spring, MD 20903
301-431-0500
FAX 301-431-4834
www.userworks.com

Executive Summary

In September 2001, the National Institute for Arthritis and Musculoskeletal and Skin Diseases (NIAMS), contracted with UserWorks to carry out an evaluation of the NIAMS Information Clearinghouse, currently operated by Eagle Design and Management, Inc. NIAMS wished to explore and define the qualitative criteria against which users judge the Clearinghouse's customer service and materials. These services include the response to inquiries from various sources, and the development, design, production, and distribution of paper and electronic materials in response to these customer requests.

The key questions in this evaluation were:

- Who are the primary and secondary users of the NIAMS Information Clearinghouse? What are the demographic profiles of these users?
- From a user perspective, what are the measureable features and characteristics of satisfactory and optimal information resources in terms of access to information, inquiry response by phone, mail, email, and fax, publications distribution, and content, reading level, and format of print and Web-based materials?
- In terms of these features and characteristics, how satisfied are Clearinghouse users?
- Are the requirements for responses to requests for information and material (that the responses be courteous, accurate, appropriate, and timely) being met?
- Are the services of the Clearinghouse cost-effective?

This evaluation was accomplished in five tasks:
- interviews with NIAMS staff, Clearinghouse employees, and representatives of the NIAMS Advisory Council, a group of volunteers for major voluntary organizations who represent patients with diseases covered by NIAMS;
- a review of previously collected quantitative data;
- surveys delivered by US mail, electronic mail, and the NIAMS Web site;
- focus groups with representative users of the NIAMS Clearinghouse; and
- follow-up interviews with users under-represented in the other tasks.

Evaluation results presented in this report are organized according to these tasks. Overall, most users were quite positive about the quality of the response they received from the Clearinghouse. Users had mixed satisfaction with the information that is produced and disseminated by the Clearinghouse. There are users at the extremes of satisfaction: those who have been helped by the Clearinghouse and are very effusive with their praise, and those who had difficulty getting the information they sought and were very critical of the Clearinghouse. In the more general surveys, and in interviews with users who are very familiar with the Clearinghouse, satisfaction was high. In the more detailed feedback heard in the focus groups, which tended to highlight the concerns of first-time users, however, there was more restrained praise and more criticisms about both the response method and timeliness, and of the nature of the information received.

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Background

In September 2001, the National Institute for Arthritis and Musculoskeletal and Skin Diseases (NIAMS), an institute of the National Institutes of Health (NIH), contracted with UserWorks to carry out an evaluation of the NIAMS Information Clearinghouse, currently operated by Eagle Design and Management, Inc. NIAMS wished to evaluate the NIAMS Information Clearinghouse in an independent and objective process to determine the effectiveness and quality of services in the areas of inquiry response and materials development. This evaluation was designed to answer questions that will help NIAMS determine whether the Clearinghouse is meeting its objectives.

NIAMS wished to explore and define the qualitative criteria against which users judge the Clearinghouse's customer service and materials. These services include the response to inquiries from various sources, and the development, design, production, and distribution of paper and electronic materials in response to these customer requests. An example of these materials include information of interest to consumers that is mailed, faxed, or appears on the Clearinghouse Web site, and that is prepared by the Clearinghouse included, such as booklets (e.g., the series "Handout on Health" and "Questions and Answers About…") and other publications within the Health Information section of the NIAMS Web site. The scope of this project excludes the evaluation of the clearinghouse's maintenance of the AR subfile of the Combined Health Information Database (CHID).

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- In terms of these features and characteristics, how satisfied are Clearinghouse users?

- Are the requirements for responses to requests for information and material (that the responses be courteous, accurate, appropriate, and timely) being met?

- Are the services of the Clearinghouse cost-effective?

This last question was further defined during joint NIAMS/UserWorks discussion of the work plan for this project to emphasize the perception of cost-effectiveness and any efficiencies and inefficiencies in the different methods that consumers use to contact the Clearinghouse. Additionally, NIAMS is interested in consumers' view of the cost effectiveness of the characteristics of the publications that make these publications

special to consumers, but more expensive. Characteristics such as bilingual publications, simple and readable format, and four-color presentation were specifically of interest. The evaluation asked if consumers considered the expenditure for these characteristics good stewardship of the Federal government's resources.

Interviews

In the first task of this project, members of the evaluation team interviewed NIAMS staff, Clearinghouse employees, and representatives of the NIAMS Advisory Council, a group of volunteers for major voluntary organizations who represent patients with diseases covered by NIAMS. The purpose of these interviews was to gather a more complete perspective of the customer service process in order to better inform the analysis of the data collected throughout this evaluation. These interviews sought to get an understanding of the types of people that contact the Clearinghouse, what their expressed needs are, and how the Clearinghouse currently serves these needs.

UserWorks evaluation team members interviewed Clearinghouse staff, especially management and customer service delivery staff, to gather more complete perspectives of the customer service process, and to better inform the analysis of reported data. The scripts for these interviews are included as Appendices A, B, and C. These interviews were audiotaped, and a NIAMS representative attended the interviews with Clearinghouse staff.

We interviewed the following NIAMS staff:
- Dr. Janet Austin, Director, Office of Communications and Public Liaison (OCPL)
- Raymond F. Fleming, Jr., Deputy Director, OCPL
- Constance D. Raab, Public Liaison Officer
- Judith S. Wortman, Technical Information Specialist
- Kelli Carrington, Writer-Health Educator
- Julie Townshend, Public Affairs Specialist
- Suzanne Melancon, Public Information Assistant
- Kim Logan, Public Information Assistant
- Margaret S. Kerza-Kwiatecki, Associate Director for Management and Operations.

These members of the Clearinghouse team were interviewed:
- Sam Beatty, Project Manager
- Judy Horman, Operations Manager, Senior Information Specialist
- Alison Soffer, Information Specialist
- Mary Vines, Information Specialist

Members of the NIAMS Advisory Council interviewed were:
- Priscilla Ciccariello, President, Coalition for Heritable Disorders of Connective Tissue
- Jean Mandeville, Osteogenesis Imperfecta Foundation

- Tamara Liller, President, National Fibromyalgia Partnership Inc.
- Oretta Mae Todd. Ph.D, RN, Arthritis Foundation
- Kathleen Ferrell, former Advisory Council member
- Amye Leong, former Advisory Council member.

The following summarizes the data collected in these interviews.

Interviewees' View of the Clearinghouse

For the most part, those interviewed for this evaluation were overwhelmingly positive in their reaction to Clearinghouse staff, seeing them as accurate and responsive to the requests of users, and congenial to work with. Staff were found to be:

- organized
- caring
- efficient
- prompt
- very dedicated
- willing to take suggestions
- interested
- cordial
- resourceful
- helpful
- thorough

- patient
- detailed
- excellent
- personable
- pleasant
- outgoing
- affable
- willing to help
- easy to work with
- committed
- positive

- having good insight
- staying one step ahead of NIAMS
- often being able to predict what NIAMS would need before it was requested.

The teamwork of the NIAMS Information Clearinghouse staff was often commented upon as a highly valued characteristic, and they were said to have met all expectations and gone beyond. Others mentioned their ability to change and adapt easily and quickly to the unexpected emergencies that often come up. They were noted for having good response time to requests, and interviewees were very impressed with their work. Management was seen as very responsive and attentive to detail. Overall, NIAMS staff felt that the Clearinghouse's effective response enabled NIAMS staff to carry out their duties more effectively, and freed them to address other tasks. Clearinghouse staff were said to have appropriate organizational priorities and the publications were thought to be of high quality. The Clearinghouse staff work independently with little direction, and achieve a high level of service.

Those interviewed agreed that the information provided to patients should include, but not be limited to, the basics of the disease: a general description of the disease, how the disease is diagnosed, what type of doctor treats the disease, and information about NIH-funded research, including clinical trials. It was important within this goal that Clearinghouse staff who interact with requestors provide a caring, responsive ear to the concerns of patient users, who often feel shunted aside and ignored by health care professionals and other more general health information services. Interviewees believed

that the tone and enthusiasm of the responses were valued as equally important to the information that was provided.

Interviewees felt it important that patients know that they are not alone, that the information that is provided to them is personalized for their particular situation, and that the information is appropriate to where they are at in terms of their disease – beginning information for those who have just been diagnosed, and more detailed information for those who have more knowledge and experience with their disease. One concern was that maintaining the personal touch in the face of increasing requests and stable (non-increasing) funding may be difficult, and may hamper the Clearinghouse's ability to provide services to users. Automation may provide services to a greater number of people for the same money, but may result in a less personal service, which it is feared may result in less satisfaction for users.

Strengths of the Clearinghouse

Most interviewees thought that the Clearinghouse is operating as well as it can, and most had very few suggestions for changing or improving its services. There was the overall feeling from the interviews that the Clearinghouse is doing a difficult job well.

All of those interviewed who had heard compliments about the Clearinghouse noted that the expressions thanked the Clearinghouse for providing information that the user had been unable to find in other information sources. According to interviewees, many compliments come from patients who are "ecstatic" to find that some information or referrals are available for them on their condition. Interviewees liked that the tone and grammar of the publications were clear, but reduced to a reading level that a wide segment of the public can understand.

There was little confusion amongst any of the interviewees about the goal of the Clearinghouse. Most agreed that the role of the Clearinghouse is to
- act as a liaison between the patient and researchers
- disseminate information on illnesses, including symptoms and treatments
- disseminate past and current research on these diseases.

One interviewee said that an important role of the Clearinghouse is to "provide hope to patients contacting the Clearinghouse" for information, to let them know that there are others who understand and appreciate the impact of a disease on an individual's life, and to provide resources to help patients manage their illnesses.

The timetable in the statement of work for the Clearinghouse contract provides guidance on the timeframes in which a variety of responses must be completed. Interviewees were satisfied with the timeframes indicated, and Clearinghouse customer service staff reported that they felt that they had sufficient time within the guidelines to adequately meet user needs.

There was little confusion reported among the customer service staff. The goals were generally believed to be understood, and many interviewees pointed to training notes,

documentation, and the Clearinghouse procedures manual as good tools for maintaining understanding. Also, the fact that the information that is provided must follow NIH guidelines for objectivity, reliability, etc., was said to help information specialists know what types of information could and could not be passed on to users.

Meetings between Eagle and NIAMS staff every other week were thought to be essential for the smooth operation of the Clearinghouse, and appropriately timed – not too often and not too infrequent. Reporting between Eagle and NIAMS was thought to be adequate, with special reports available when needed. Meetings between the Advisory Council, NIAMS staff, and the Clearinghouse staff were also called useful.

Identified problems

The few complaints from users that interviewees had heard related primarily to two problems: lack of data about little-known diseases, for which little information exists, or frustration that there is no answer to a specific question – usually a request for a referral to a medical doctor or care facility in their area. This service – the availability of a medical doctor to speak/email with, to assist in diagnoses and provide more specific information – was referred to as the service that may most help patients that is not currently available through the Clearinghouse. However, interviewees felt that this service would not be within the scope of the current Clearinghouse, or within NIH guidelines to fulfill. Interviewees identified the Clearinghouse's inability to meet all of the users' needs as the major challenge.

One interesting incident was noted in the interviews when complaints about the Clearinghouse were requested. Several interviewees mentioned that there had been a misunderstanding about the handling of donation checks that had not been processed in a timely manner. Each person that mentioned the problem also mentioned that the issue had been cleared up, and that no further incidents had occurred.

There was a concern that while the Clearinghouse's publications provide good basic information, that there is little in the way of more substantive information for those whose would request it. Also, as NIH is very conservative on treatment issues, there was a concern that not as much information is being provided to patients as could be, because NIH/NIAMS tends to report only what is scientifically verified rather than what may be occurring in individual treatments. This concern conflicts with NIH's role to report only the scientific bases for treatments, but nevertheless a few interviewees are troubled by the policy.

Another concern was that although the Clearinghouse requires the publication and updating of many titles, there are a large number of diseases that still do not have a publication. Interviewees felt that publications from NIH/NIAMS are valuable beyond the information they provide, especially for rare or little-known diseases, because the publications
- give national visibility to a disease
- are nationally-based, rather that regionally- or locally-based

- provide expertise that even most national voluntaries cannot
- help to educate doctors and other health professionals
- reach broader contacts
- have greater distribution networks
- contain the most up-to-date research information.

Objections were raised to generalizations in the publications, but it was said that there are few instances where this happens. Inclusion of a list of related resources was considered very valuable.

Some interviewees discussed graphics resulting in a range of responses. Some felt that graphics support would be one area where Eagle could help NIAMS more, while others felt that using graphics support was a rather hit-or-miss proposition – it depended very much on the particular graphic artist that would be available. While interviewees indicated that in the past, original writing from a former Eagle staff member had not met needs and expectations, these problems seem to have been resolved, and NIAMS staff interviewed for this evaluation were very happy with the editing service that they now receive from Eagle.

The reports generated by Eagle were praised for being thorough and helpful, but interviewees were concerned that the time spent developing them may outweigh their importance and the need for the information. Interviewees from both NIAMS and Eagle indicated that the standardization of reports has encouraged the belief that the reports are easy to put together, but it is not clear that this is true.

Those interviewed were concerned that current information about research may be slow in getting to the NIAMS Web site. Interviewees felt that most of the information currently available on the site is dated. With the increased use of the Internet, there is a heightened expectation for the timely publication of updated information. Interviewees felt that having publications on the Web site with last revision dates in 1998 or 1999 would not meet this expectation.

Those interviewed and individuals represented in the materials provided by the Clearinghouse do not represent racial diversity although interviewees indicated that progress was being made to reach out to more minorities. One interviewee talked in particular about the new Many Shades of Lupus publication as a "step in the right direction," reaching out to a wider population while not offending them by talking down to them. Several interviewees thought that there should be more publications of this type, to more targeted populations, and providing more bilingual publications.

There was some confusion about what the Clearinghouse is, in the sense that many interviewed did not know where NIAMS ends and the Clearinghouse begins. This is emphasized by the fact that the Clearinghouse does not have a public building or face; does not have their own Web site; and that most people interviewed associate the work of the Clearinghouse and that of NIAMS as being the same. (A search for the Clearinghouse that one interviewee completed online returned no results.)

At least one interviewee felt that it was a challenge for the Clearinghouse to maintain its role as an information service while not taking valuable money away from research, while another thought it a significant challenge for the Clearinghouse to balance growth and outreach to more users with its current resources to handle increased requests. Another thought that a great challenge for the Clearinghouse is how to get information about the Clearinghouse or NIAMS and the diseases they cover to members of the general public who do not have Web access, or who do not live near a large medical center, or who haven't already heard of NIH. Many users, one interviewee said, have heard of NIH "as a cloud in the sky," but do not see it as a system that they as a patient could plug into. Sometimes, even knowledgeable people have trouble understanding NIH, as the names of the Institutes are long and there is an extensive use of acronyms. Interviewees felt that members of the general public do not have a strong sense of the information sources at NIH and of how the general public can participate in clinical trials. They thought that members of the general public sometimes erroneously link or confuse NIH with the Centers for Disease Control, and generally may have negative feelings about NIH.

Another challenge to the Clearinghouse is the fluctuating workload, and the low degree to which the Clearinghouse is able to plan for the unexpected. For example, if a media publication includes the Clearinghouse telephone number, the Clearinghouse may or may not know about the publication in advance, and may or may not have prepared for the influx of calls that would result. Other challenges include:
- unlimited appetite that some patients may have for information on their disease
- need to continually update the large number of publications
- need to translate publications into numerous languages
- need to address low literacy issues and to present information in a variety of formats to reach users at all literacy levels.

Funding and logistics were identified as great challenges for the Clearinghouse. Interviewees noted that it takes lots of money to create materials, promote the Institute and its publications, hire and train staff, buy media space, and do their mailings. Also, finding effective ways to get information in specific areas where people are not in the "main stream" of information and inventing ways to make people become more aware of NIAMS is difficult. One interviewee summarized this by saying that trying to reach everyone, getting information out to patients in the most economical way, and getting information into the right hands are the biggest challenges.

One interviewee felt that a common statement in NIAMS materials – that patients should talk to their personal doctor about what they had read – was potentially damaging because it carried two assumptions: One, that people have a doctor, and Two, that people can afford to go to that doctor. Many people with these chronic diseases, this interviewee noted, are on low or fixed incomes, and are unable to afford going to a doctor. Often, they have no insurance or are underinsured for their condition. Assuming that patients will be able to take a team approach to treatment with their doctor is not accurate.

Interviewees also believed that an erroneous perception exists, that because many of the diseases covered by NIAMS are genetic, the effect of these diseases is less that the effect of an infectious or acute disease. Interviewees felt that this was inaccurate, as many people with chronic diseases feel that they have much to contribute to a job or their community, but are unable because of the severe and chronic pain they suffer. Because of this assumed lessened impact, interviewees believed that there is an assumption that funding can or should be limited to chronic diseases, and that this is another reason why NIAMS has little money for publications and research.

There was a desire among interviewees that the Clearinghouse should continue to reach out to new users, providing more information for health professionals, and that more publications be written and revised. Outreach to a predominantly poor African American and Hispanic community at the Cardozo clinic in Washington, DC was mentioned as a positive move. There was also a desire that NIH/NIAMS provide more information through television, which would have "overwhelming" access; through radio; and that it should become more known through word of mouth, which was called "the biggest tech tool for people who are ill."

One interesting comment was that a challenge to the Clearinghouse exists in reaching out to minority users, in that members of racial minorities often have an inherent suspicion of government agencies. One interviewee reported that among African American communities in particular, there is a feeling that "you (as a government employee) may be doing a good job, but you are not doing it for me (or those in my racial group)." There was no suggestion to overcome this suspicion, other than to be aware that this opinion exists and to work consistently in spite of that barrier, and hope that individual users see the good that is being done.

One identified inefficiency was in talking with customers. Allowing non-interactive methods of taking orders is much more efficient, but less personally interactive and customized.

Suggestions for improvement

It was suggested that the Clearinghouse make efforts to contact doctor's offices, libraries, pharmacies, exhibits, community health fairs, support groups, barbershops, hairdressers, etc., to improve outreach "where the patients are." Interviewees thought that the Clearinghouse should produce more print material and radio and TV public service announcements, and team with reputable non-profit, non-government organizations that are working on illnesses to raise awareness and combine resources. One NIAMS staff interviewee said that it would be beneficial to the Clearinghouse's outreach efforts if more than one staff member were allowed to attend conferences; there is currently a contractual limitation to allow only one. Often, when the single staff member is talking with a conference participant, managing the display booth, or even taking a bathroom break, there are numerous missed opportunities to talk with health professionals.

A few logistical recommendations were made. One interviewee suggested providing cell phones to staff while exhibiting at a conference, to facilitate most efficient communication. Interviewees suggested providing information specialists more and better access to more recent information, such as reference materials, articles, and the National Library of Medicine databases, which currently can only accessed on the NIH campus and not at Eagle. It was also suggested that information specialists receive additional training opportunities and news dispatches from NIAMS. (NIAMS has been forwarding the NIH E-clips service email to the Clearinghouse each day, but the emails are unreadable by Clearinghouse staff because Eagle staff email addresses are identified as not being on the NIH server, and therefore staff are blocked from reading them.) There are currently a large number of misdirected phone calls with no identifiable pattern, which interrupt and cause additional work for the information specialists.

Suggestions for improving the Clearinghouse included locating its offices on the NIH campus, and more clearly communicating changes in Clearinghouse leadership or staffing turnover to NIAMS staff. Even better, a training session at Eagle would help those NIAMS staff who do not have direct contact with the Clearinghouse know who at Eagle is in charge of what, and who to call at Eagle if they need someone. Also, a phone list which would include the names, titles, and phone numbers of all Clearinghouse staff would assist NIAMS staff in getting a good mental model of the Clearinghouse and of keeping track of the sometimes-changing names and roles of staff members.

Also, the wide variety of areas with which information specialists are required to be familiar results in people who have a wide knowledge of some areas, but are pulled into a number of areas with which they are simply not able to have the same familiarity. One interviewee complimented the information specialists as "able to hold lots of information at their fingertips." However, many also recognized that it is very difficult to have the level of detail that all consumers would want; for some illnesses, there would be lots of information, while for others, the information is less detailed. Additionally, there is concern on the part of one interviewee that the information specialists may lack skills, and may not always be trained as thoroughly as would be desired. Also, they may not be able to perform thorough research to each request. These barriers could be overcome by ensuring that staff have thorough customer service training, research training, and cultural and sensitivity training.

Another suggested option for assisting customers whose immediate request is outside the scope of the Clearinghouse is the creation of shorter factsheets with resources for low-incidence diseases. There may also be some complaints from those users who feel that the Clearinghouse is not answering their question "immediately," but these users may only provide mail or email contact information, which requires time to deliver the answer. A comment was also made that some users may want more information about their condition, but that they are not unsatisfied with what they have received. In these cases, referrals to other organizations are made to provide the user with additional avenues for information. There is also the feeling that users of the Clearinghouse are grateful for the sympathy and empathy that the Clearinghouse staff provide in their

responses, even when they do not get the answer to the questions they were originally asked.

One thing that would help information specialists would be to include or improve access to medical journals online, so that referrals could be better made to patients; to provide access to more publications in more languages, and to translation services; and to create or distribute a list to the information specialists of the doctors at NIH and their specialties, especially noting those doctors who would be willing to consult with patients.

Many interviewees mentioned positively the booklet "How to Find Medical Information" as an example of a booklet that provided good information for those new to a chronic disease; it was suggested that more publications like this could be created, if funds were available. Suggestions for pamphlets included teaching patients how to be self-advocates in their health care, or how to participate in research studies, or how to find a doctor.

Data Review

In conjunction with the background interviews, members of the UserWorks evaluation team reviewed the currently collected and reported data on the Clearinghouse. UserWorks acquired and analyzed the data currently on hand to create and enhance the profile of the current Clearinghouse customer, included below. Quantitative data analysis in these areas supplemented the collection and analysis of qualitative data in the previous interview task.

The data analyzed included monthly and annual reports of the Clearinghouse during the timeframe July 1, 1998 to June 30, 2001, which included the following data points:

- Requestor name
- Organization
- Address
- City, state, zip
- Phone and fax
- Email
- Customer type
- Request topic
- Type of request
- Organization type
- Inquiry screening time
- Inquiry response time
- How caller learned about NIAMS
- Inquiry methods (mail, phone, fax, email, etc)
- Number of publications ordered and which ones.

Identifying information, such as name, address, phone, etc. were not available for this review, and that not all information was available for all entries.

Monthly reports on NIAMS Web site logs from March 2000 to August 2001 were also analyzed; these reports included such information as:

- Number of hits
- Most requested pages
- Single access pages
- Most downloaded file types

- Activity levels by day and time, etc.

Additionally, we received slides from an earlier usability test of the NIAMS Web site conducted in February of 2001 by Human Factors International. The slides provided to UserWorks detail HFI's segmentation of users and goals of the NIAMS Clearinghouse and Web site. HFI divided NIAMS users into primary groups:
- General public
    - Patients in protocols
    - Other patients
    - Friends and family of patients
- Administrative personnel
- Media
- Professionals
    - Researchers
    - Health providers
    - Students
    - Association representatives
    - Government agencies
    - Patient advocates
    - Clearinghouse information specialists

We find this information consonant with our research; however, the majority of the users who contact the Clearinghouse for information are within the general public user group. While our data collection efforts drew from users in each of the groups listed above, the majority of the feedback we received, and subsequently the focus of our results, was related to the general public user group.

NIAMS Information Clearinghouse User Profile

This profile represents a general description of users of the NIAMS Information Clearinghouse as of Fall 2001. Information sources drawn upon to compile this profile include interviews with Eagle staff, NIAMS staff, and members of the NIAMS Advisory Council, and the data review, both detailed above. (Note that all statistics are from the 2000-2001 contract year.)

Contacting the Clearinghouse

While many NIAMS users are contacting the Clearinghouse by telephone, e-mail, FAX, and mail (28,560), a clear majority of users are accessing information via the Web site (1,493,753 user sessions[1]). Other than the Internet, the single most utilized method to contact to the Clearinghouse is via telephone (combined 12,832), followed by standard mail (9,574) and email (5,327). The number of visitors to the Clearinghouse Web site

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[1] One user session is defined as a single visit to any page within an individual Web site from the same IP address within a given amount of time. In WebTrends, the default time period for a user session is 30 minutes.

has continued to climb by approximately 10 percent each month through the end of the 2001 contract year.

Interviewees said that for the most part, users are more likely to use telephone and mail to communicate with the Clearinghouse are older, while younger requestors may be more likely to use email and the Web. Some callers, however, will ask while on the telephone if the Clearinghouse has a Web site that has information available, and will request the Web site URL so that they may access information online.

Many of the issues that are strong with non-Web requestors, such as general information about arthritis and osteoarthritis, are not the primary diseases about which users of the Web site are downloading information. Web site users appear to be looking for information on diseases such as fibromyalgia, lupus, and shoulder and knee problems.

The Web site of the Clearinghouse is regarded positively as a good communications and marketing tool. One interviewee thought that users may be more aware of the Clearinghouse and its services because of the Web site, and the 24 hour a day, 7 day a week access that it provides. Another said that the Web site is user-friendly, clean, and simple. They liked that users could print publications directly off the Web for immediate review.

Interviewees saw the multiple ways of contacting the Clearinghouse (phone, mail, e-mail, FAX, Web) as very good, and helping to increase the number of requestors contacting the Clearinghouse. One interviewee had the impression that the interactive voice response system was an efficient way of collecting requests from those users who didn't need to talk to an information specialist.

Most contacts to the Clearinghouse via mail, telephone, and email are made in the late summer and early fall – August, September, and October. Web requests also showed high numbers of contacts in these months, but after a dip in December the increasing trend in numbers of visitors matched and overcame the fall statistics.

Typical customer

The typical NIAMS Information Clearinghouse customer is a patient with a medical condition covered by NIAMS (74.7%). These conditions are chronic, often causing severe pain and other serious symptoms, and without cures. These patients come from every age, gender, ethnic background, region, education level, and economic status in the United States; however, it is the perception of interviewees that the population is skewed toward older adults, and that there are few users younger than 25. They also said that there are current few minority users of the Clearinghouse, but the numbers of these customers, especially African American and Hispanic customers, are rising. The users' literacy levels range from very low to very high; many customers may need publications that are directed to those with low comprehension skills, while others may desire very scientific, technical articles or publications. Most users are from the United States, although there are a very small number of international users. Some users are aware of

the scope and mission of NIAMS and of NIH as a whole, while others have no familiarity with the organizational structure.

Most patients are seeking:
1. a medical diagnosis based on self-observed symptoms
2. a referral to a local doctor who can become their general practitioner or specialist
3. enrollment and eligibility information on becoming a patient of and involved in a medical treatment program at the National Institutes of Health.

As these pieces of information are not within the scope of the Clearinghouse or NIH to disseminate, part of the assessment of the performance of the Clearinghouse is based on the information specialists' clarity in communicating the boundaries of information that NIH/NIAMS disseminates, in assisting patients in locating information that perhaps the patient didn't know existed (like a publication addressing their disease, or a clinical trial for their disorder), and referring patients to specific resources. Some patients requesting information are looking for clinical trials that may result in research findings related to their disease. Many are "desperate for information" about their conditions, and have been referred to the Clearinghouse by their doctor, treatment partners, or community health clinic. Many patients, especially the elderly, may have few resources—personal (in the form of friends and family), economic (money or health insurance), or emotional.

Health care professionals comprise another important user group for the NIAMS Clearinghouse (14.2%). These customers are looking for definitive, unbiased, and accurate information. They often come into contact with the Clearinghouse at conferences or exhibits, which are organized and executed by Clearinghouse and/or NIAMS staff. Health professionals are often looking for one of two kinds of information: publications to order in bulk from the Clearinghouse for distribution to a number of their patients, or medical research information and referrals.

Other callers include family members (1.9%) or friends (.2%) of patients. In many of these cases, the caller may not know exactly what the patient's diagnosis is, or the patient themselves may not know what disease they have. These friends and family members need introductory information, which the Clearinghouse is easily able to provide.

Other users of the Clearinghouse include
- members of the media (1.2%)
- Federal employees or legislators (1.1%)
- students (.9%)
- librarians and other information professionals (2.2%)
- scientists who are seeking research or grant information (.4%)
- educators (.6%)
- members of a support group
- a person who wants to start a voluntary organization.

NIAMS staff, themselves users of the Clearinghouse, often request that publications be sent to individual customers, conferences, or community health fairs, and handle all media and Federal inquiries.

Most requestors of the NIAMS Information Clearinghouse (44.9%) heard about it from media listings, including journals, newspaper articles, magazine articles, newsletters, and radio and television articles. The NIAMS Web page is also a large generator of requests, with 17.6% of users who are tracked by the order tracking system coming from the NIAMS Web page. Others contact the Clearinghouse to order publications they read about in other NIAMS publications (9.7%), and from directory listings (5.6%); referrals from other Federal agencies (3.3%); or referrals from health care professionals (1.9%).

Unusual requests to the Clearinghouse come from patients who ask about associations between various activities, foods, or exposures and their disease; and prison inmates (who are sometimes repeat customers).

Patients' Interaction with the Clearinghouse

According to the interviewees, patients often see the Clearinghouse as a last resort for information. The patients are looking for medical advice or information, a diagnosis, or referral to any place or person that might help them. They are often in moderate to severe pain, distressed, frustrated, or upset (one said "grouchy"), not only by the condition they have but also by the lack of information and resources that may be available. They have often looked for information on their disease in other places and not been able to find helpful results. In some cases, users may be frustrated, fearful, and ashamed, especially if their disease is genetically based; they may fear being "found out," or the publicity that may go with others' knowledge of their disease.

Interviewees saw a primary role of the Clearinghouse to orient patients to NIH, to NIAMS, and to the limits of the role that the Clearinghouse can play in providing referrals and information. To this end, information specialists explain the role of the Institute in researching new treatments, and dispel the inaccurate notion that they believe many patients have of NIH as "the national hospital." The information specialists explain the role of clinical trials in researching new treatments, and the limitations that are placed on potential participants. They explain that the Clearinghouse is not permitted to refer patients to individual doctors or hospitals (or to warn away from "bad" doctors or hospitals), but that their role is to supply referral information for organizations that may in turn make referrals. These include support groups, national voluntaries, and other external organizations.

Clearinghouse staff that take calls try to give patients calling some sense of hope, and to empower them to manage their condition and its effects. They make an effort to understand, letting the patients talk and tell their story, and listen carefully to callers and writers to make sure that the patient's needs are being understood and addressed. Often callers are irritated because they have called other numbers already, and been transferred to other organizations several times before reaching the Information Clearinghouse. Patients are often desperate for any information about their disease. They don't want to sound stupid, and indeed don't want to be unknowledgeable about their condition, but find that locating information about their condition is a challenge. They often find it difficult to articulate their needs. Since few outlets are prepared to help them, they are

eager to find someone who can talk to them about their disease, and will not "talk down" to them.

One interviewee stated that occasionally she talked with callers who were discouraged in their attempts to reach the Clearinghouse because they were not able to reach a live person with whom to talk, but she said that this happens only rarely. Another interviewee thought that NIH/NIAMS might not receive as many calls from patients with less well-funded research into their disease, because there is the impression that "NIH doesn't care" or that there are a number of other sources that are providing more information. Some interviewees expressed that there is a clear perception by patients that the focus of the Clearinghouse is on arthritis and related diseases, and that NIH is imposing and not accessible.

Request Responses

The vast majority of the customer requests are categorized as "standard," that is, requiring only a prepared response (92.6%). Other responses require non-inventory materials or a customized response. It was the experience of interviewees that orders from the Clearinghouse are received very quickly, often within days.

As most orders to the Clearinghouse require only standard publications, the response time required to respond to these orders is likewise short: 96.1% require less than 2 minutes to screen, and 92.8% of orders require less than two minutes for a response.

The number of publications disseminated continues to climb, although the number of publications disseminated solely by Eagle vs. those disseminated by the Government Publications Center in Pueblo, CO, is difficult to determine from the available reports.

Requested Publications

Most requested publications via non-Web methods (phone calls, mail, e-mail, etc.):
1. Do I Have Arthritis? (96,451)
2. Osteoarthritis Handout on Health (43,177)
3. Systemic Lupus Erythematisus Handout on Health (31,673)
4. How to Find Medical Information (26,565)
5. Questions and Answers: Fibromyalgia (16,562)
6. Questions and Answers: Sjogren's Syndrome (12,326)
7. Rheumatoid Arthritis Handout on Heath (11,531)
8. NIAMS Bookmark (11,358)
9. Questions and Answers: Knee Problems (9,272)
10. What Black Women Should Know About Lupus (8,936).

Most requested publications via Web:
1. How to Find Medical Information (172,441)
2. Questions and Answers: Knee Problems (126,509)
3. Questions and Answers: Fibromyalgia (97,008)

4. Lupus Handout on Heath (90,880)
5. Questions and Answers: Gout (72,666)
6. Questions and Answers: Psoriasis (73,664)
7. Questions and Answers: Shoulder Problems (63,158)
8. Questions and Answers: Raynaud's Phenomenon (54,526)
9. Questions and Answers: Acne (54,223)
10. Questions and Answers: Polymyalgia Rheumatica and Giant Cell Arteritis (49,927).

[Note: reports marked with an asterisk (*) are underreported due to an incomplete report.]

When comparing the number of publications disseminated by mail and those disseminated by the Web, it can be stated that Web dissemination consistently provides 2 to 5 times the number of publications disseminated by mail in a given month.

Surveys

In this task, UserWorks focused on the development of measures and criteria that described the characters and qualities that create an optimal experience for users of the Clearinghouse. For example, to what extent and in what ways are users concerned about hours and methods of access, timeliness and thoroughness of clearinghouse response, quality and timeliness of the distribution of materials? Publication-specific measures may include users' perception of satisfaction with the content of specific NIAMS materials, or the propriety of the reading level and format of the current publications.

We used a traditional questionnaire methodology to assess user satisfaction in the areas of service and materials. In conjunction with NIAMS, we were able to create a questionnaire that met the requirements of the National Institutes of Health's Office of Management and Budget's approval for surveys.

In this task, the evaluation team sought responses from those individuals who ordered or printed their materials off of the Web, who emailed their questions and received responses the same way, as well as those who used the more traditional mail and telephone contact methods. The final, distributed forms of these surveys are included as Appendices D, E, and F.

Paper survey

We first developed a paper-based survey for users that contacted the Clearinghouse by any method, and received materials in the mail as a result. Customers who received material from the Clearinghouse received a paper questionnaire with their mailed materials from February 1 to April 4, 2002 . The total number of questionnaires sent was 1606, and 312 were returned, for a response rate of approximately 20 percent. This number is extremely high for the return of a paper response form, where typical response rates are two to three percent.

Customers were asked to volunteer to respond to the questionnaire. They were also asked to volunteer their name and contact information so that we could contact them and ask them to participate in the focus groups, if the user was in the Washington DC Metro area. The responses were received for two months at UserWorks' offices in Silver Spring, and the entered into a Microsoft Access database. As identifying information was not required, each return was tracked by the postmark on the envelope.

In total, 312 paper questionnaires were returned. Respondents represented 44 states of the United States, Puerto Rico, and the foreign countries of Argentina, Australia, Canada, and Nigeria. The most highly represented states were California (33), New York (25), Florida (22), Illinois (18), Maryland (17), and Pennsylvania (17).   20 did not have postmarks. Of the 32 respondents that included their contact information, only two were located in the Washington DC Metro area. One was contacted but did not respond to our request to participate in the focus group.

Of the 312 who responded to the paper survey, a variety of methods were used to contact the Clearinghouse:
- 163 contacted by telephone
- 115 by US mail
- 13 by fax
- 12 by email
- 11 used the Web site
- 1 listed the library as their contact source
- 3 listed no source.

NOTE: For all responses, respondents could select as many responses as appropriate; thus totals may exceed the number of responses received. Respondents could also choose to not respond to a specific question.

Respondents were asked to describe their purpose in contacting the Clearinghouse:
- 278 sought general disease information
- 29 sought clinical studies
- 3 sought press releases
- 33 contacted the Clearinghouse for another purpose.

Respondents ranked their impressions of the Clearinghouse on a four-point Likert scale:
- 2 selected very helpful
- 287 said helpful
- 19 said somewhat helpful
- 1 answered not helpful
- 1 wrote in that "sooner would be better."

The services that respondents sought included:
- 305 sought publications
- 20 sought database searches
- 9 sought referrals

- 5 sought other services.

Respondents were asked to rate their experience with the Clearinghouse in the areas of information received, content, and quality of the text and illustrations. On a scale of 0 to 5, with 0 being very dissatisfied and 5 being very satisfied, Clearinghouse users rated the information they received at 4.8.
- 260 were very satisfied
- 42 were satisfied
- 6 were neutral
- 2 were dissatisfied
- 2 were very dissatisfied.

The content was rated at 4.8 out of 5.
- 253 were very satisfied
- 53 were satisfied
- 5 were neutral
- 1 was very dissatisfied.

The text and illustrations were rated at 4.82.
- 237 were very satisfied
- 44 were satisfied
- 7 were neutral
- 3 were dissatisfied
- 1 was very dissatisfied
Of those receiving large print materials,
- 26 were very satisfied
- 3 were satisfied
- 1 was neutral
- 1 was dissatisfied
- 1 was very dissatisfied

Comments received include the following (NOTE: All comments, except where otherwise noted, are from patients.):

"I really appreciate the information (pamphlets, copies, circulars, etc.) which you sent to me. Your office is very efficient in sending me the information that I need so bad. Your office is very courteous in answering the telephone. If I were to rate you on a scale from 1 – 10, 10 being the highest, I would definitely give you a rating of 10. The information that I received from you was most helpful and rewarding. I could have never obtained this information from no doctor or any other source. Thanks for a job well done."

"In the adult retirement park we have two organizations…[that] have a coffee every Wednesday... It is a great time to exchange information. I am taking this opportunity to thank you for all the different pamphlets that people have sent to

us. In no time at all, everyone here will go through it." – Health education professional

"I am beyond grateful for your services. I'm learning more because of your literature than from my doctor."

"Very, very wonderful, extremely helpful service. Through your publications, we are teaching…adolescents…on subjects like acne, sprains, knee problems… Thank you." – Health education professional

"I deal with the publication clearinghouses for all the NIH institutes. NIAMS, in service and product, is one of the best. Thanks!" – Health professional

"It was on the right topic, but did not cover what I asked for, clinical trials of alternative[s] to hip replacement surgery."

"Would like to reach by telephone but can't seem to reach a human through your phone tree. Can't say if timely, can never speak to a human."

"Content and text and illustration were too simplistic."

"[Information received] not on topic demanded."

"Publication missing, none of those received really answer the big question: Do I have arthritis? NIH booklets good, but medical journal articles too full of medical terminology. Text fine, but photocopied photos very hard to see."

"Very little info and Q&A page sent. Did not receive any info on ongoing clinical trials for my area."

"I had a Baker's cyst. By the time I received this information, I'd had the surgery done."

"Very little info & Q&A page sent. Did not receive any info on ongoing clinical trials for my area. Do you do recommendation s or send lists for doctors in my state who are experienced in treating such illnesses?"

Web survey

We developed a Web-based survey for those users who contacted the Web site for their information. We received a total of seven responses to the survey, which is a much smaller number than anticipated. The lack of ability to publicize the survey to users of the Web site, aside from the positioning of a link on the Health Information page, led to this small number of returns. The site was tested several times, from multiple locations and computers, to insure that the survey technology was working.

Those who did respond to the survey indicated that they found the site via the NIH Web site (6 respondents); other government sites, such as Healthfinder (4 respondents); through links on other Web sites, such as osteonecrosis.org and arthritis.org (3 respondents); and through a search engine (1 respondents: Google). (NOTE: For all responses, respondents could select as many responses as appropriate; thus totals may exceed the number of responses received. Respondents could also choose to not respond to a specific question.) Nine respondents indicated that they used the Web site to read publication (6 respondents) or print publications (3 respondents), on topics including alternative treatments for conditions, condition management information, hip replacement, eczema, moles, referrals to doctors, and lupus. Six respondents sought information on NIAMS programs or research, 4 sought information on NIAMS, and 2 sought information on news and events. Twelve respondents had not visited the Web site before the visit about which they answered the questionnaire.

Of those responding to the survey, there was a wide divergence of opinion on the quality of the publications found online. While most respondents were positive, there were those who were not satisfied with the presentation or content of the online publications. In the table below, the number of respondents answering each question is shown.

	Very satisfied	Somewhat satisfied	Neutral	Somewhat dissatisfied	Very dissatisfied
Publication provided information on the right disease	3	3	1		2
Publication was easy to understand	3	3			1
Text was easy to read	4	2		1	
Illustrations were easy to see	3	2	2		

We were able to perform follow-up interviews with some of these respondents; more detailed responses are included in the description of these interviews below.

Email survey

We developed an email-based survey for those users who received emailed information in response to a contact. In a similar way to the Web survey, UserWorks created an online survey that email users could access by clicking on a like included with each email response. UserWorks received a total of five responses to the survey, which again is a

much smaller number than anticipated. The survey site was tested several times, from multiple locations and computers, to insure that the survey technology was working.

Those who did respond to the survey were, overall, generally pleased with the information they received. (NOTE: For all responses, respondents could select as many responses as appropriate; thus totals may exceed the number of responses received. Respondents could also choose to not respond to a specific question.) Respondents indicated that they were referred to the NIAMS email through the NIAMS Web site (2 respondents), through other online sources (2 respondents), through another government link (1 respondent).   Five respondents received a response within one to two days; 2 others received a response in less than one day. Six respondents thought that this response was very efficient, while one found it only somewhat efficient. Five respondents thought that the email included an appropriate point of view, while one felt that the view was somewhat appropriate, and one found it only reasonable. Six respondents found the references in the email very appropriate; one found the references somewhat appropriate.

All respondents received links in their email reply; two indicated that they had already investigated these references, while for 5 respondents these references were new. Five respondents found the information appropriate, and said that it "pointed them in the right direction." Of the three respondents who had previously contacted the Clearinghouse before, one found the email service significantly better, one found it somewhat better, and one found it about the same as their previous contact (Web, telephone, and email). We were able to perform follow-up interviews with some of these respondents; more detailed responses are included in the description of these interviews below.

Focus Groups

Overview of focus group sessions

As part of the NIAMS Clearinghouse evaluation, UserWorks conducted two focus groups with Clearinghouse customers, all of whom were people living with diseases and conditions addressed by NIAMS. The purpose of the focus groups was for recent Clearinghouse customers to evaluate, based on their experience and needs, various aspects of the NIAMS Clearinghouse.

The main discussion points covered in the focus groups included evaluation of the following: interacting with the NIAMS Clearinghouse by telephone, e-mail, or the Web site; Clearinghouse publications; the process of receiving information from the Clearinghouse; and (very briefly) the NIAMS Web site.

Method

UserWorks held two focus group sessions, one on the evening of March 25 and the other during the afternoon of March 26. Sixteen participants in total (eight for each focus group) took part in these sessions. A UserWorks focus group facilitator moderated the

focus groups, and was assisted by a UserWorks specialist who recorded notes and provided technical assistance.

UserWorks recruited study participants from a pool of potential NIAMS Information Clearinghouse users using our recruitment database. The recruiter conducted short telephone interviews with each candidate to identify candidates' eligibility for the study. During the interviews the recruiter followed a screener developed for the NIAMS focus groups. See Appendix G for the screener.

All participants in the focus groups were people living with one of the diseases or conditions covered by NIAMS. Each focus group represented a diverse range of characteristics including age, gender, and racial or ethnic groupings, and health issue of concern. See Appendix H for the demographic characteristics of the focus group participants.

After determining a candidate's eligibility to participate in the study, the UserWorks' recruiter asked each participant to contact the NIAMS Clearinghouse. UserWorks instructed each participant to request information or to ask a question related to the personal health issue identified during the screening interview. The recruiter also assigned to each participant one of three specific methods for contacting the Clearinghouse—telephone, e-mail, or the NIAMS Web site.

UserWorks assigned participants the task of contacting the Clearinghouse up to two weeks prior to the focus groups sessions. Three to four days prior to the focus group sessions, UserWorks' staff made a follow-up call to participants reminding them of their appointments and asking participants to bring any materials received from the Clearinghouse to the focus group session.

Upon arrival at UserWorks, participants were asked to read and sign a video release form. See Appendix I for the video release form. Participants also were asked to complete a short questionnaire about their recent contact with the NIAMS Clearinghouse. See Appendix J for the questionnaire and responses. The script for the focus groups is included as Appendix K.

UserWorks hosted the focus groups in their conference room equipped with audio and video recording devices and a one-way glass through which the assistant and NIAMS staff could observe the sessions. Each session lasted approximately two hours.

Highlights from focus group sessions

Listed below are key findings from the focus groups.

- Clearinghouse staff perceived as friendly, helpful, and knowledgeable.

- Contacting the Clearinghouse on the free phone number caused some confusion.

- Turnaround time between requesting materials and receiving materials from the Clearinghouse did not meet customers' expectations.

- NIAMS publications *Questions and Answers* and *Handout on Health* viewed as containing basic information useful to new patients, families, and friends. However, these publications contained little new information for the focus group participants who already had a basic understanding about their personal health issue.

- *NIAMS Information Packets* not considered very usable.

- Favorable reviews, with some reservations, given to the publications and e-mails intended for outreach to ethnically and racially diverse populations.

- Content needs unmet by the NIAMS publications included up-to-date information and more information on the latest research, causes, treatment, long-term effects, prevention, and diet for various conditions and diseases.

- Although interest in accessing up-to-date health information was high, health information on the NIAMS Web site not considered very up-to-date or accessible.

Specific findings

Discussed in more detail under Specific Findings are details about the major themes and related issues that arose during the two focus groups. The discussion is organized into the following subsections: Interacting with the NIAMS Clearinghouse, Receiving information from the NIAMS Clearinghouse, and Assessing NIAMS publications.

Interacting with the NIAMS Clearinghouse

Talking with Clearinghouse staff
All participants who spoke with Clearinghouse staff reported that the staff was friendly, helpful, and knowledgeable. Participants said that their questions were answered directly and that the staff was accommodating, listened to callers, and understood the questions that were asked. The only reservation expressed came from a participant who contacted the Clearinghouse a second time when the requested materials did not arrive as anticipated. Although the staff person was friendly, the participant was not comfortable with the advice to "be patient."

Calling the Clearinghouse
Two participants reported problems initially telephoning the Clearinghouse. One participant was not familiar with the prefix "877" for toll free numbers. Therefore, she added the prefix "800" in front of "877." Another initially found that the phone he dialed did not work. However, both participants successfully telephoned the Clearinghouse on their second attempt. While reviewing the Web site, one participant pointed out the importance of including the phone number in

digits and not just letters (877-22NIAMS), particularly for those who have cognitive problems.

Using the Clearinghouses' phone message service
Only one participant called the Clearinghouse during nonworking hours and connected to the phone message service. Although she only listened to the introductory phone message, she reported favorably that the message clearly indicated the Clearinghouse's hours of operation.

E-mailing the Clearinghouse
Participants reported that e-mailing the Clearinghouse resulted in prompt replies from the Clearinghouse with the turnaround time ranging from the day the information request was sent to two days following the request. Various participants mentioned that the replies from the Clearinghouse were generally helpful and contained references to the NIAMS Web site and recommended resources outside of NIAMS. Two participants mentioned that the messages they received were in English and Spanish. The bilingual messages were surprising because they had not requested information in Spanish.

One person, who received a reply referencing the NIAMS Web site, indicated that the response was somewhat general, rather than specifically indicating where on the site to find the information he requested.

Requesting information on the NIAMS Web site

When recruited, one-third of the participants were assigned the task of going to the NIAMS Web site to request information or to ask a question related to their health concern. In response to this task, some participants looked for health information on the Web site, some ordered or tried to order publications on the Web site, and others tried to send, while on the Web site, an e-mail request for information from the Clearinghouse.

When listing characteristics about using the Web site, the following comments were made: not the most usable site, the list of health information is limited, lots of scrolling and sifting through information, long, verbose, did not see an expected link to Medline, could not find information about a health problem, and did not know how to order information. Overall, the Web site was graded with average to low marks by the focus groups even though participants expressed strong interest in using the Web site.

One participant described how he found information about shoulder pain on the Web site, and that he considered the material concise and informative. He also tried to order, as indicated on the Web site, the publication about shoulder pain, but never located where to order the publication. In addition, he never realized that the information about shoulder pain that he read on the NIAMS site was the same information he would received if he had been able to order the publication

on shoulder pain. And this person identified himself as an experienced computer specialist.

Receiving information from the NIAMS Clearinghouse

Commenting on the turnaround time for receiving information
Turnaround time between requesting materials and receiving materials from the Clearinghouse did not meet customers' expectations among participants in the focus groups. Participants felt strongly that the turnaround time was slow, and as a result, felt the Clearinghouse had not delivered the level of customer service that they expected.

Several participants had not received their requested information in the timeframe indicated to them by the Clearinghouse and/or in the timeframe they expected from a Clearinghouse located in the same geographic where they live or, in one case, in comparison to other health information clearinghouses. Participants generally agreed that they should have received materials from the Clearinghouse within 5-7 days of ordering.

One participant reported that he had called the Clearinghouse on March 14 to request information on osteoarthritis, and he had not received anything by the day of the focus group, March 25.

Assessing NIAMS publications

During the focus groups, participants reviewed NIAMS publications related to their particular health concerns and to other diseases and conditions addressed by NIAMS. In particular, participants critiqued various *Question and Answer* and *Handout for Health* booklets, *NIAMS Information Packages*, and the recent publications, *The Many Shades of Lupus*, the bilingual, *Do I Have Arthritis?,* and *How to Find Medical Information.*

Meeting customers' expectations about health information content
Participants voiced several expectations regarding NIH and the NIAMS publications. No one debated the point when one participant emphasized her expectation that information from NIH can be trusted. Likewise, no one mentioned any doubts about the accuracy of the content in the NIAMS publications even though the importance of credible medical information was brought up by one participant and others casually mentioned that you have to be careful about the source of health information found on the Web.

Yet, participants felt strongly that the content of the NIAMS publications fell short of their expectations. Participants expected that NIH information would contain the latest, most up-to-date information, including breakthrough medicine. A publication date of January 1999 was viewed as outdated by the focus group participants.

Moreover, many participants, most of whom considered themselves quite knowledgeable about their particular health concern, felt strongly that the NIAMS publications lacked information or sufficient information about the latest research, causes, treatment, long-term effects, prevention, and diet. Participants appreciated the contents of the booklet, *How to Find Medical Information,* particularly because it was "how to" information and it listed Web resources.

Commenting on the *Question and Answer* and *Handout for Health* booklets
Participants commented very positively about how the information is organized, the type size, and how understandable the information is in the *Question and Answer* and *Handout for Health* booklets. Useful features specifically identified by participants included the table of contents and the tables summarizing information.

Participants generally perceived the *Questions and Answers* and *Handout on Health* booklets as containing basic information useful to new patients, families, and friends. However, most participants felt these publications contained little new information useful to them because they already had a basic understanding about their particular health issue. One participant commented, "I have more information in my head than what's here."

In addition to the importance of matching the depth of information to the user's needs, one participant pointed out that she perceived the intended audience for the *Handout on Health* on atopic dermatitis to be that of parents of children with eczema. For example, this participant said the text, "'Make sure their nails are cut,' is not useful advice to me as an adult living with eczema." The participant suggested a separate publication on eczema for adults.

Commenting on the *NIAMS Information Packages*
For some participants the *NIAMS Information Packages* appeared interesting because they contained more in-depth information. However, some participants had difficulty determining who was the intended audience—the general public or medical professionals—because of the technical language and graphics.

All agreed that the presentation of the information was a barrier to usability. Participants pointed out that the packages lacked a table of contents, sequential and logical page numbering, logically ordering of information, and readable type size, graphics, and text. As one participant stated in reference to the poor quality of the photocopied pages of the *NIAMS Information Packages*, "I'm astonished at how bad the reports are."

Commenting on the *The Many Shades of Lupus* and *Do I Have Arthritis?*
Participants offered favorable reviews, with some reservations, for the publications intended for outreach to ethnically and racially diverse populations. Although no one in the focus group was personally dealing with lupus, participants agreed that the information in *The Many Shades of Lupus* was well

organized, understandable, and provided a good introduction to the problem. Participants gave similar positive feedback about the bilingual publication, *Do I have Arthritis?*

One participant was confused by the title, *The Many Shades of Lupus*, and expected that the title referred to different varieties of lupus. Two participants found the subtitle of the lupus booklet, "Information for Multicultural Communities," to be limiting. One participant mentioned that she did not think the pictures in the booklet had any point.

One of the reviewers of *Do I have Arthritis?* aptly pointed out that Spanish speaking people come in a variety of colors, contrary to the cover's illustration. Another thought that combining English and Spanish text in one booklet wasted paper because a person would need information presented in only one language. One person questioned the rationale of the booklet's use of graphics in which opposing pages contained the same, but differently sized illustrations, the larger graphic appearing in the Spanish text and the smaller graphic appeared in the English text.

Evaluating the general design of the NIAMS publications
Although participants did not have, in general, high expectations for the design of the health information materials, they were extremely critical of the poor design of the NIAMS Information Packages. In addition, more than one participant commented that the design of the various booklets, for example, *How to Find Medical Information*, was not very interesting. Another participant made a similar comment about a *Question and Answer* booklet, "The cover is a bit bland, but it is what you expect from a medical brochure."

As for ways to improve the design of the publications, participants suggested more graphics, for example, pictures of different types of rashes experienced with eczema, and more tables summarizing information. Small font size and poor photocopies were simply not acceptable.

Follow-up Interviews

In addition to the user survey methods outlined above, we conducted follow-up interviews with users whose views we felt had not been adequately or deeply enough explored. The script for these follow-up interviews is included as Appendix L. To include the perspectives of additional users, especially those such as health professionals who constitute a significant user group but whose views had not been fully included in the paper, Web, or email surveys, or in the focus groups. These interviews served to supplement the feedback we received through the focus groups.

The users interviewed in this task were garnered from a list of health providers provided by NIAMS and from those who had submitted contact information in email, Web, or paper surveys. UserWorks conducted email and telephone-based interviews with these

users to determine their perceptions of how the Clearinghouse currently functions, their understanding of the Clearinghouse's mission when it functions optimally, and their ideas of how the processes could be improved. They were queried about their present use, any difficulties they have encountered, and any preferences for the system if they could direct future changes. Data obtained from these interviews was used to clarify what customers believe to be the ideal response for users who have approached the Clearinghouse.

The views that we heard during the follow-up interviews were largely consonant with the information that was collected though other phases of the evaluation. Interviewees were generally very satisfied with the service and information that the Clearinghouse provides. They are very satisfied with the information resources that are provided, and report that other health groups have been interested and appreciative of the publications. Both agreed that more publications, on more topics, were needed as funds became available to produce them.

In these interviews, the staff were found very helpful, and the response time adequate. All of those interviewed in this round used the Web to get information, often daily if not weekly. When they need several copies of a publication, they order via telephone or the Web and receive the publications through the mail. They were all satisfied with the response time, although one noted that she "always plans ahead" and generally is not in a hurry for the publications.

Some interviewed saw the publications as oriented to patients, helping them "gain a better understanding of their disease so they can make educated decisions, and cope more effectively." The health professionals use the publications as supplemental educational information during workshops and health fairs, and to find information to give to patients at presentations and office visits. They felt that the publications, especially the newer ones, were very attractive, and the large print was reported to be great for older patients. Those who has received information packages found their publications hard to read. The publications are thorough, although they are undated so it is difficult to find out how recent the information is.

Others saw the publications as oriented toward health professionals, and believed that some of the publications contained information that was too technical or advanced for most patients, who may have a lower literacy level. One felt that the older publications are not as colorful, and therefore not as appealing, but are oriented to audiences who are not worried about "glitz and glamour." If the publications are more visually attractive, this interviewee felt, "as a government agency, they [NIAMS] would just get criticized."

The health professionals that we talked with indicated that the patients they dealt with had "no idea what NIAMS is." They felt that the Clearinghouse is primarily oriented toward health professionals, health educators, and nursing students. They do refer patients to the Web, but many become frustrated trying to figure out acronyms and good places for information. The information of most interest to patients, they said, was introductory and in-depth information on illnesses, and the latest research findings on a particular disease. To help these patients, interviewees said that the Web site could be

improved by making the navigation easier, and condensing information under more clear and specific topic areas.

Conclusions

The key questions in this evaluation, and our conclusions, are presented below.

1. **Who are the primary and secondary users of the NIAMS Information Clearinghouse? What are the demographic profiles of these users?**

For the full NIAMS Information Clearinghouse profile, see page 14. In summary, the primary users of the Clearinghouse are patients, friends, and family members. Most are seeking information about medical conditions, referrals to medical professionals, or information about becoming a patient in a medical treatment program at NIH. Secondary users are health professionals, members of the media, information professionals, and others. These users are seeking information about the medical conditions covered by NIAMS.

The vast majority of users contacting the Clearinghouse use the Internet; telephone, mail, and email, in that order, are the next most popular contact methods.

2. **From a user perspective, what are the measureable features and characteristics of satisfactory and optimal information resources in terms of access to information, inquiry response by phone, mail, email, and fax, publications distribution, and content, reading level, and format of print and Web-based materials?**

Speed of response: Users want to be able to access information about their disease quickly. Many expressed the feeling that since their concern about an illness or diagnosis was serious enough to prompt them to seek out and contact the Clearinghouse, the speed with which they received information was of critical importance. Optimally, users would receive their information instantly, or with minimal delay. Some users expressed an understanding that, when working at an information center that receives a large number of requests, there may be a delay in the processing of an individual request. These users were satisfied with a minimal to moderate delay in the receipt of materials. Five to seven days was indicated as an acceptable response time.

Method of access: Users surveyed implemented telephone, U.S. mail, email, and the Internet to access information.

Publications content: Because the information is being requested from NIH, there are high expectations for the information. Users expect the information to be accurate, credible, and trustworthy. They are expecting information about their disease, including a description of the symptoms of the disease, and information about how to prevent or best manage the disease. They expect information to address their expressed problem, to

speak to their stage of the disease (newly diagnosed, managing for several years, in a flare-up, etc.), and to contain the latest, most up-to-date medical research.

Reading level and format: Users expected the publications of NIH/NIAMS to be understandable and organized. They expected each publication to begin with a table of contents, which identified specific page numbers, and preferred informationally rich graphics, especially illustrations of a given disease and its effects.

   3. **In terms of these features and characteristics, how satisfied are Clearinghouse users?**

Overall, users had mixed satisfaction with the information that is produced and disseminated by the Clearinghouse. There are users at the extremes of satisfaction: those who have been helped by the Clearinghouse and are very effusive with their praise, and those who had difficulty getting the information they sought and were very critical of the Clearinghouse. In the more general surveys, and in interviews with users who are very familiar with the Clearinghouse, satisfaction was high. In the more detailed feedback heard in the focus groups, however, users were more restrained in their praise and more likely to be critical of both the response method and timing, and of the information received.

Speed of response: Most users in the interviews and surveys were satisfied with the time that it took for them to receive materials that they requested from the Clearinghouse. Most of the users in the focus groups, however, felt that the turnaround time was slow, and were disappointed in the service they had received. They had contacted the Clearinghouse from 7 to 10 days before the focus group, and had not received their publications within the timeframe indicated by the Clearinghouse, or by the timeframe they considered appropriate.

Method of access: Users were very satisfied with the methods of access available to them. Those that utilized the telephone and spoke with a Clearinghouse representative were very complimentary of their knowledge and professionalism. Those who emailed the Clearinghouse received prompt replies that contained helpful information. Some users who went on the Clearinghouse Web site were able to access the information available. However, other Web site users found the NIAMS Web site very difficult to use in the tasks of finding health information and ordering publications from the Web site. When asked, users said that they found the information available on the Web site verbose and hard to read online.

Publications content: Many users found the introductory information provided in common Clearinghouse publications, such as the Questions and Answers and Handouts on Health, trustworthy, helpful, and informative. They found that the more extensive information provided in information packages overwhelming and technical, and expressed a need for an intermediate level of information, beyond the introductory but less technical than the journal articles included in the packages.

Users were disappointed by the generality of the information, which did not answer or address many of their specific questions. They felt that many publications were out of date, and did not include new research information. Users found health management and prevention information lacking in Clearinghouse materials, and would like to see more specific explanations of the dos and don'ts for a particular illness, the affect of diet and exercise, triggers for outbreaks or fare-ups, and information describing how to live with the disease.

Reading level and format: Users were generally very happy with the format of the Questions and Answers and Handout on Health publications. They were less satisfied with the Information Packages, which were found to lack a table of contents, be illogically assembled, and most importantly, to be poorly photocopied to the point of being illegible. Newer publications, such as *The Many Shades of Lupus* and the bilingual *Do I have Arthritis?* Were found to be well-organized and understandable.

   4. **Are the requirements for responses to requests for information and material (that the responses be courteous, accurate, appropriate, and timely) being met?**

Courteous: Users clearly felt that Clearinghouse staff were courteous when delivering information. Praise for the Clearinghouse staff was clear and consistent throughout this evaluation.

Accurate: The information provided was found by the users to be accurate, but incomplete. They expected and desired more up-to-date information, especially addressing the prevention and management of their chronic conditions.

Appropriate: The information booklets provided by the Clearinghouse were judged to be appropriate for those new to a disease; the information packages, however, were found to be too technical and inappropriate for laypeople.

Timely: Users were satisfied with the response they received from requests delivered via email and the Internet. They expressed concern, though, about the time required to receive publications via U.S. Mail.

   5. **Are the services of the Clearinghouse cost-effective?**

The services of the Clearinghouse are provided to a large number of Americans, and have found an international audience. Users felt that the Clearinghouse was performing a great service on what was assumed to be a tight budget. Attempts to reach out to new customers in the minority community were received positively. However, as the Clearinghouse must balance their commitment to non-Web users who contact the Clearinghouse by mail or telephone, the usage statistics clearly indicate that vastly more people contact the Clearinghouse via Web than by telephone or mail.

Given the ever-increasing expense of providing information specialists to respond to off-line inquiries, warehouse staff to process orders, and paper and postage costs, considering methods to improve the online experience and direct more customers to receive their publications online may provide more cost-effective information dissemination.

Other major conclusions found in this evaluation include:

- Confusion among those not affiliated with or familiar with the Clearinghouse about the job of the Clearinghouse. The lack of a mission statement and unfamiliarity with the term "clearinghouse" leave many customers unclear about the purpose of the Clearinghouse.
- People also do not seem to understand the range of Clearinghouse services that are offered. For example, approximately 11% of the participants in the paper survey contacted the Clearinghouse for "other purposes," which may include research, and few participants in the focus group were aware that the Clearinghouse would conduct research on a specific topic.
- Likewise, there is a lack of clarity about where NIAMS ends and where the Clearinghouse begins. Even among those familiar with NIAMS and the Clearinghouse, there is substantial ambiguity about the differentiation of roles.
- Many patients, health professionals, and patient advocates interviewed found the recommendation, often-repeated in NIAMS publications, for patients to discuss this information with their doctor to be unhelpful. In many cases, they felt, patients cannot rely on their doctors, either because they cannot afford to go to the doctor on a regular basis or because their doctors may not be specialists in this area.
- Despite the fact that the Clearinghouse is clear in not providing referrals to doctors or diagnoses, these are still the most-often asked questions of the Clearinghouse. A more clear statement of these limitations, especially posted on the Clearinghouse Web site, may reduce these inquiries.
- Many of the users who requested prevention or condition management information may find helpful information from other NIH Institutes. Inter-Institute linkages, especially to institutes such as the National Center for Complimentary and Alternative Medicine, may be able to provide helpful information for patients with some diseases.
- While the reaction to the production of publications for ethnically and racially diverse audiences was positive, the response to the information provided was mixed. They were not confident that the publications accurately portrayed the communities to which they were directed, and there was concern that publications that were directed toward both majority and minority audiences (such as the bilingual booklet *Do I Have Arthritis?*), should be separated to be more focused and specific.

Appendix A
Script for Interviews of NIAMS Staff
October 12, 2001

I. Participant Intro—5 minutes

Thanks for participating today. Have you ever participated in an interview like this before?

As you know, I am a member of a team that is helping NIAMS to evaluate the NIAMS Information Clearinghouse from the users' perspective. Today I would like to talk with you about your role with NIAMS, your interaction with the NIAMS Information Clearinghouse, and if and how you interact with customers of the NIAMS Information Clearinghouse. I want to get your perspective on how we can help the NIAMS Information Clearinghouse provide the best services possible to its users. We will be finished in about an hour.

I do want you to remember a few things as we talk:

− There are no right or wrong answers; I am not testing you, but asking for your opinion as an expert.
− We are interested in your feedback some ideas that I might have, whether positive or negative.
− I want you to feel free to comment about anything that affects your interaction with the NIAMS Information Clearinghouse, even if it's not something that I ask directly about.
− As you know, I am audio taping the session. That is for us to review what happened. You signed the consent form earlier and you also remember that if you want, you can quit at any time.
− Everything you say is confidential in the sense that your name will not be associated with what you say. What you report will only be used in combination with the feedback we get from other people, and not reported back to anyone at NIAMS.

Do you have any questions before we begin?

II. Interview about usual role and interaction - 50 minutes

1. **Tell me about your role in the NIAMS. What is your job?**

2. **In your job, what types of interactions do you have with the NIAMS Information Clearinghouse staff?**
   How often do you interact with them? What is your impression of the professionalism of the staff? From your position, what do you see as the most positive characteristics of the staff? Are there any negatives?

3. **In your job, do you interact with NIAMS Information Clearinghouse customers?**
   How often does this happen? How long are these interactions? Do you feel like you get to know the users?

4. **What do you see as the goal of the NIAMS Information Clearinghouse?**

5. **Tell me what you think a typical NIAMS customer is like. Can you give me a profile?**
   What do you think other customers are like?

6. **Tell me about your VISION of the perfect customer interaction, from beginning to end.**

- Potential follow up questions:
    - What kinds of items, or services, or information should customers have access to? How would orders get received, filled, and distributed?
        - What's the most common thing that people ask for now? What are some of the most unique or unusual things that people have asked for?
        - Do you feel that the NIAMS Information Clearinghouse is adequately serving customers? Where are the efficiencies and inefficiencies? (What parts of the process do you think go well, and which are costly in terms of time or money?)
        - Do you think that the NIAMS Information Clearinghouse is operating as well as it could?
    - What tools (technology or otherwise) do you think NIAMS customers use on a daily basis? Weekly basis? Once in a while?
    - How would you judge the quality of the information or the services being provided to customers?
    - Do you hear much interaction or responsiveness from users of the NIAMS Information Clearinghouse? Do you get complaints or thank yous?

7. **Tell me about the biggest challenges that the NIAMS Information Clearinghouse faces.**

- Potential follow up questions:
    - How much of a factor are the time / cost / staff resources (or lack thereof) in meeting these challenges?
    - Is there very much confusion about the goals of the NIAMS Information Clearinghouse? Do you think that the NIAMS Information Clearinghouse is meeting its goals?
    - How does the performance of the NIAMS Information Clearinghouse affect your work?

8. **What would you say are the most important barriers to implementing the vision you have talked about?**

- Potential follow up questions:
    - Do you think that these barriers presently have an impact on users?
    - Do you have any ideas for how these barriers could be overcome?
    - If you could redesign the Clearinghouse to make it work better in any way, what would you do?

IV. Wrap-up –5 minutes

9. **Are there any questions you would like to ask me, or additional comments that you would like to make?**

Thank you so much for your time today. Your input has been very valuable in our evaluation.

Appendix B
Script for Interviews of Eagle Staff
November 1, 2001

I. Participant Intro—5 minutes

Thanks for participating today. Have you ever participated in an interview like this before?

I am a member of a team that is helping NIAMS to evaluate the NIAMS Information Clearinghouse from the users' perspective. Today I would like to talk with you about your role with the NIAMS Information Clearinghouse, how you interact with customers, and get your perspective on how we can help NIAMS and the NIAMS Information Clearinghouse provide the best services possible. We will talk about your experiences and opinions in several different areas, to get an idea of how you do your job on a day-to-day basis. We will be finished in about an hour.

I do want you to remember a few things as we talk:

− There are no right or wrong answers; I am not testing you or your abilities, but asking for your opinion.
− We are interested in your feedback both positive and negative. We will be using what we talk about in this interview to inform us about the users of the Clearinghouse. But we will also use what we hear in these interviews to determine if there are other areas of information about those users that are important but that are not currently collected, so that we can ask users those questions later during our evaluation.
− Neither my job nor your job depends on your feedback or comments being positive or negative. What is happening is that you are helping us gather information about the NIAMS Information Clearinghouse, how it works now, and how to make it work better. The best thing you can do for both of us is for you to be candid.
− Everything you say is confidential in the sense that your name will not be associated with what you say. What you say will only be used in combination with the feedback we get from other people, and it will not reported back to your boss or to your manager or to NIAMS. It will not be associated with you as an individual, and our discussion will not affect your job in any way.
− I want you to feel free to comment about anything that affects your interaction with users of the NIAMS Information Clearinghouse, even if it's not something that I ask directly about.
− As you know, I am audio taping the session. That is for us to review what happened. You signed the consent form earlier and you also remember that if you want, you can quit at any time.

Do you have any questions before we begin?

II. Questions about usual role and interaction - 50 minutes

1. **Tell me about your role in the NIAMS Information Clearinghouse. What is your job?**

2. **In your job, how often do you interact with customers?**
   How long are these interactions? Do you feel like you get to know your users?
   Do you think you know what your customers are trying to do?

3. **Tell me what you think a typical NIAMS customer is like. Can you give me a profile?**
   What do you think other (non-typical) customers are like?

4. **Tell me about your typical day, from beginning to end.**

- Potential follow up questions:
  - Describe the workflow for a typical customer request. How does the order get received, filled, and distributed?
    - What's the most common thing that people ask? What are some of the most unique or unusual things that people have asked?
    - Do you feel that there is enough time to adequately serve customers? Is there too much time? Where are the efficiencies and inefficiencies? (What parts of the process do you think go well? What parts take a lot of time and could be handled more efficiently?)
    - How much time is required for each part of the process? Do you think that this it too long, too short, or about right?
  - What tools (technology or otherwise) do you use on a daily basis? I'm thinking here about notepaper, forms, computer programs for notes or orders, PDA and items like that. Weekly basis? Once in a while?
  - Do you think that your customers use technology and other tools to interact with the NIAMS Information Clearinghouse? Here I'm thinking of E-mail, the Web site, and anything else that you realize that customers are using to accomplish their tasks.
  - How would you judge the quality of the information you are providing to customers? Does your team include members who handle quality control or quality assurance? Is this done internally or externally? What types of things are you checking?
  - Do customers tell you about other interactions that they have had with the NIAMS Information Clearinghouse or with other ways that they have sought information and, if so, what do they say? Do you get complaints or "thank yous"? What about getting feedback from them after the process is complete? Do they ever follow up to let you know what has happened with them?

5. **Tell me about the biggest challenges that you face.**

- Potential follow up questions:

- How much of a factor are the time / cost / staff resources that you have?
- Are the goals of the NIAMS Information Clearinghouse clear?
- Do you ever inherit a prior project (either from another person at the NIAMS Information Clearinghouse or from NIAMS) that needs to be redone or carried forward? How do you manage that?
  - Is there information available to you so that you know where to pick up the project?
- How does interaction with other team members affect your role?
  - Does everyone adhere to a consistent set of guidelines for interacting with customers? What factors hinder such consistency?

6. **(Optional, depending on circumstances) As we have talked you have indicated that there are several places where you think the current process should be changed or modified. What would you say are the most significant barriers to implementing the changes you have talked about?**

- Potential follow up questions:
  - Do you think that these barriers presently have an impact on users?
  - Do you have any ideas for how these barriers could be overcome?
  - If you could redesign the whole system to make it work better, what would you do?

III. Wrap-up –5 minutes

7. **Are there any questions you would like to ask me, or additional comments that you would like to make?**

Thank you so much for your time today. Your input has been very valuable in our evaluation.

Appendix C
Script for Interviews of NIAMS Council Members
November 1, 2001

I. Participant Intro—5 minutes

Thanks for participating today. Have you ever participated in an interview like this before?

As you know, I am a member of a team that is helping NIAMS to evaluate the NIAMS Information Clearinghouse from the users' perspective. Today I would like to talk with you about your role with and relationship to NIAMS, your interactions with the NIAMS Information Clearinghouse, and if and how you interact with customers or potential customers of the NIAMS Information Clearinghouse. I want to get your perspective on how we can help the NIAMS Information Clearinghouse provide the best services possible to its users. We will be finished in about an hour.

I do want you to remember a few things as we talk:

− There are no right or wrong answers; I am not testing you, but asking for your opinion.
− We are interested in your feedback on some ideas that I have, whether positive or negative.
− I want you to feel free to comment about anything that affects your interaction with the NIAMS Information Clearinghouse, even if it's not something that I ask directly about.
− As you know, I would like to have an audiotape record of the session (for both). That is for our company to be able to review the information you gave us. Is it okay with you to be audio taped? (if interviewing by phone). You signed the consent form earlier (if in person). Also remember that if you want, you can quit at any time.
− Everything you say is confidential in the sense that your name will not be associated with what you say. What you report will only be used in combination with the feedback we get from other people, and not reported back to anyone at NIAMS.

Do you have any questions before we begin?

II. Interview about usual role and interaction - 50 minutes

1. **Tell me about your role related to the NIAMS Council. What is or was your position as a Council member? How long have you been/were you a member of the Council?**

2. **In that role, what types of interactions do you have with NIAMS Information Clearinghouse staff?**

How often do you interact with them? What is your impression of the professionalism of the staff? From your position, what do you see as the most positive characteristics of the staff? Are there any negatives?

3. **In your job, do you interact, directly or indirectly, with NIAMS Information Clearinghouse customers?**
   How often does this happen? How long are these interactions? Do you feel like you get to know the users?

4. **What do you see as the goal of the NIAMS Information Clearinghouse?**

5. **Tell me what you think a typical NIAMS customer is like. Can you give me a profile?**
   What do you think other (non-typical) customers are like?

6. **Tell me about your VISION of the perfect customer interaction, from beginning to end.**

- Potential follow up questions:
    - What kinds of items, or services, or information should customers have access to? How would orders get received, filled, and distributed?
        - What's the most common thing that the customers you know ask for now? What are some of the most unique or unusual things that users request or have asked for?
        - Do you feel that the NIAMS Information Clearinghouse is adequately serving customers? Where are the efficiencies and inefficiencies? (What parts of the process do you think go well, and which are costly in terms of time or money?)
        - Do you think that the NIAMS Information Clearinghouse is operating as well as it could?
    - What tools (technology or otherwise) do you think NIAMS customers use on a daily basis? Weekly basis? Once in a while?
    - How would you judge the quality of the information or the services being provided to customers?
    - Do you hear much interaction or responsiveness from users of the NIAMS Information Clearinghouse? Do you hear complaints or compliments?

7. **Tell me what you think the biggest challenge is that the NIAMS Information Clearinghouse faces.**

- Potential follow up questions:
    - How much of a factor are the time / cost / staff resources (or lack thereof) in meeting these challenges?
    - Is there very much confusion or many other opinions on the Council about the goals of the NIAMS Information Clearinghouse? Do you think that the

NIAMS Information Clearinghouse is meeting its goals? Do you think that other Council members would agree?

- How does the performance of the NIAMS Information Clearinghouse affect your role?

8. **What would you say are the most important barriers to implementing the vision you have talked about?**

- Potential follow up questions:
  - Do you think that these barriers presently have an impact on users?
  - Do you have any ideas for how these barriers could be overcome?
  - If you could redesign the NIAMS Information Clearinghouse to make it work better in any way, what would you do?

IV. Wrap-up –5 minutes

9. **Are there any questions you would like to ask me, or additional comments that you would like to make?**

Thank you so much for your time today. Your input has been very valuable in our evaluation.

Appendix D
Paper-Based Survey

Comments on the NIAMS Information Clearinghouse

We are interested in determining if NIAMS Information Clearinghouse users are satisfied with the services provided. Below are areas on which we would appreciate your comments. Please comment only on your current experience with the NIAMS Information Clearinghouse.

To better understand your comments, please check the box indicating

1. Method used to contact the NIAMS Information Clearinghouse
Telephone
Fax
U.S. Mail
Email
Web site

2. Purpose for contacting the NIAMS Information Clearinghouse
General diseases information
Clinical studies
Press releases
Other

3. Impression of the NIAMS Information Clearinghouse
Helpful (courteous & timely)
Somewhat helpful
Not helpful

4. Services received
Publications
Database search
Referral
Other

5. We would like to know how satisfied you were with the response from the NIAMS Information Clearinghouse. Please comment on the degree of satisfaction for the following (Very satisfied, somewhat satisfied, neutral, somewhat dissatisfied, very dissatisfied).
Information was on the right topic
Content was easy to understand
Text and illustrations were easy to see (regular/large print)

If you want to know more or wish to make additional comments please call 888-558-7872 (free call) or email niams@userworks.com or write to NIAMS Evaluation, c/o UserWorks, 1738 Elton Road, Suite 138, Silver Spring, MD 20903. We would be happy to receive your comments.

Appendix E
Web-Based Survey

Comments on the NIAMS
Health Information Web Site

We appreciate your feedback on how the NIAMS Web presence is meeting the needs of its users. If you would answer our questionnaire as you complete this visit to the NIAMS Web site, it would help us to improve services for our users.

Below are a number of areas on which we would appreciate your comments. Please comment based only on your CURRENT experience with the NIAMS Web site.

1. How did you find the NIAMS Web site?
I knew the address
   How?
Through the NIH Web site
Through another government link
   Which one?
Through a search engine
   Which one?
Other
   Please describe

2. What did you do on the NIAMS Web site?
Read publications
  Which ones?
Printed publications
  Which ones?
Ordered materials
  Which ones?
Sought information about NIAMS programs or research

Sought information about NIAMS
Sought information about news or events
Used the e-mail contact information to contact NIAMS directly.

If you used NIAMS publications, please tell us if the publications met your needs.
Publication provided information on the right disease
Publication was easy to understand
Text was easy to read
Illustrations were easy to see
       Very satisfied
       Somewhat satisfied
       Neutral
       Somewhat dissatisfied
       Very dissatisfied

Please tell us any further details that seem appropriate.

3. Have ever gotten materials from this Web site, or from the NIAMS Information Clearinghouse, before?
Yes No

If you have previously contacted the NIAMS Information Clearinghouse, how did you make contact?
Web site
Telephone answering machine during the day
Telephone answering machine during the evening or nighttime hours
Telephone with a real person
Postal mail
E-mail
FAX
Other, please describe:

How does this experience compare with the former experience(s)?
Significantly better
Somewhat better
About the same
Somewhat worse
Significantly worse

Please tell us any further details that seem appropriate.

 4. Is there other information that you would like on the Web site?

If you are interested in helping us further by answering some additional questions, please give us the following information so we can contact you.

Name
Street address
City
State
Zip
Phone Number
E-mail

SUMBIT

Appendix F
Email Survey

Comments on the NIAMS
Information Clearinghouse E-mail Response

Public reporting burden for this collection of information is estimated to average 5 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. An agency may not conduct or sponsor, and a person is not required to respond to, a collection of information unless it displays a currently valid OMB control number. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden, to: NIH, Project Clearance Branch, 6705 Rockledge Drive, MSC 7974, Bethesda, MD 20892-7974, ATTN: PRA (0925-0486). Do not return the completed form to this address.

Below are a number of areas on which we would appreciate your comments. Please comment based only on your CURRENT experience with the NIAMS Information e-mail response.

1. How did you find us to send an e-mail?
I knew the address
            How?
Through the NIH Web site
Through the NIAMS Web site
Through another government link
            Which one?
   Other
            Please describe

2. How long did it take for you to receive this return e-mail from NIAMS Information
 Clearinghouse (time from your original inquiry)?
Less than one day
One to two days
Less than a week
One to two weeks
More than two weeks

3. How would you judge this length of time?
Very efficient
Somewhat efficient
Reasonable

Somewhat inefficient
Very inefficient

4. Did the e-mail that was sent to you seem to have an appropriate point of view?
Very appropriate
Somewhat appropriate
Reasonable
Somewhat inappropriate
Very inappropriate

5. If you received references to further sources of information, did these seem appropriate?
Very appropriate
Somewhat appropriate
Reasonable
Somewhat inappropriate
Very inappropriate

6. What references were sent to you?

7. Had you already investigated these references to find an answer to this problem?
Yes, I had previously investigated these references.
No, these references were new to me for this problem.

8. Besides the references, was there any other information that was sent to you?
Yes, there was other information.
No, there was no other information.

9. If yes, did that information seem appropriate to the questions you asked?
Very appropriate
Somewhat appropriate
Reasonable
Somewhat inappropriate
Very inappropriate

Please tell us any further details that seem appropriate.

10. Have ever gotten materials from the NIAMS Information Clearinghouse, before?
Yes No

If you have previously contacted the NIAMS Information Clearinghouse, how did you make contact?
Web site
Telephone answering machine
Telephone with a real person
Postal mail

E-mail
FAX
Other, please describe:

11. How does this experience compare with the former experience(s)?
Significantly better
Somewhat better
About the same
Somewhat worse
Significantly worse

Please tell us any further details that seem appropriate.

If you are interested in helping us by answering some additional questions, please give us the following information so we can contact you.

Name
Street address
City
State
Zip
Phone Number
E-mail

SUBMIT

Appendix G
Focus Group Screener

Appt. Date & Time: ___,_____@_____

Directions Sent: _____   Recruiter: _ Reminder Call: _

National Institute of Arthritis & Musculoskeletal & Skin Diseases (NIAMS)
C. Mariel – Test Administrator
Monday, March 25 – Tuesday, March 26, 2002
Sixteen (16) participants needed
Silver Spring, MD; 1½ to 2 Hours; $75.00

Name: _____

Male ☐   Female   ☐

Daytime Phone # _____

Evening Phone # _____

1. Do you have any health problems related to the Musculoskeletal system or the skin?

   ☐   Yes
   ☐   No (Terminate)

2. What is the name of the health problems that you have?

   ☐   Acne
   ☐   Arthritis
   ☐   Bunions
   ☐   Fibromyalgia
   ☐   Hair loss
   ☐   Knee, hip or shoulder problems
   ☐   Osteoporosis
   ☐   Psoriasis
   ☐   Scoliosis
   ☐   Other _____

3. Which of these problems has a medical doctor diagnosed and which ones have you identified on your own?

☐ Doctor diagnosed _____
☐ Self diagnosed _____

4. Have you ever tried to find information about any of these health problems?

      ☐ Yes
      ☐ No (Go question 6)

5. Which of the following ways have you tried to find information?

☐ Talking to a doctor or health professional at a clinic, hospital or work site
☐ Looking at books at the library or a bookstore
☐ Contacting support groups or organizations focused on a specific health issue, such as the American Arthritis Association
☐ Looking for information on the Internet
☐ Talking to friends, relatives or colleagues who have similar problems
☐ Contacting the National Institute of Health
☐ Requesting information from a health information clearinghouse

6. Which of the following is your preferred method when looking for health information?

      ☐ Telephone
      ☐ E-mail
      ☐ Internet

7. What is the highest level of education you have completed?

      ☐ High school
      ☐ Some college   Years completed _____
      ☐ Trade School
      ☐ Associates degree
      ☐ Bachelor's degree
      ☐ Advanced degree

8. Which of the following categories includes your age?

      ☐ Under 18 (Terminate)
      ☐ 18 – 24
      ☐ 25 – 35
      ☐ 36 – 45
      ☐ 46 – 60
      ☐ Over 60

9. Which of the following most closely reflects your racial and/or ethnic background? (Recruit a mix)

☐ Asian
☐ Black or African American
☐ Caucasian
☐ Hispanic or Latino
☐ Other ＿＿＿＿

10. What is your occupation? ＿＿＿＿

11. What languages do you read? ＿＿＿＿

12. How long have you been using email?

☐ Do not use
☐ Less than 6 months
☐ More than 6 months

13. Excluding email and instant messages, approximately how many hours per week do you spend on the Internet?

☐ Do not use
☐ Less than 2 hours
☐ More than 2 hours

14. The study session will be video taped. Only the team working on this project will use the tape and your name will not be associated with the tape or other data in any way. You will be asked to sign an informed consent form. Would you be willing to be video taped?

☐ Yes
☐ No (Terminate)

15. How would you like the directions to our office sent to you?

☐ Email   Address   ＿＿＿＿

☐ Fax   Number   ＿＿＿＿

☐ Over Phone

☐ Not Needed

PLEASE NOTE THE FOLLOWING:

To participate in this focus group we will need you to contact a health information clearinghouse within the next 24 hours. It should take less than 10 minutes of your time.

We would like you to contact the clearinghouse by:

☐ Telephone – 877-22-NIAMS or 301-495-4484
☐ E-mail – niamsinfo@mail.nih.gov
☐ Internet – www.nih.gov/niams

You will need to ask a question or request information from the clearinghouse about one of the health problems that you previously mentioned. You are free to ask any question or to request that you want related to your specific health problem. Information from the clearinghouse is free. You do NOT need to tell the clearinghouse that you a participating in a focus group. We will contact again in approximately 24 hours to see if you have had an opportunity to contact the clearinghouse.

PLEASE BRING THE INFORMATION YOU RECEIVE FROM THE CLEARINGHOUSE WITH YOU TO THE FOCUS GROUP.

Appendix H

Demographic Characteristics of Focus Group Participants

Demographics of Focus Group I

P	Health Problem	Method of Diagnosis	Gender	Age Group	Race Ethnic Group	Occupation	Education	E-mail experience	Web experience	Previously looked for health information about problem	Methods used to look for health information
#1	Osteoporosis	Doctor	F	Over 60	Caucasian	Retired	Beyond Bachelor's	Over 6 months	Over 2 hours/week	No	NA
#2	Eczema	Doctor	F	46-60	African American	Executive Secretary	Bachelor's	Over 6 months	Over 2 hours/week	Yes	MD, Web, People, CH
#3	Arthritis	Doctor	F	46-60	African American	Nurse	Bachelor's	Over 6 months	Over 2 hours/week	Yes	MD, Books, People, CH
#4	Eczema	Doctor	F	18-24	Asian	Research Associate	Beyond Bachelor's	Over 6 months	Over 2 hours/week	Yes	People
#5	Back	Doctor	M	46-60	Caucasian	Marketing/Sales Manager	Some college	Over 6 months	Over 2 hours/week	No	NA
#6	Arthritis	Doctor	M	46-60	African American	Package Handler	Some college	Over 6 months	Over 2 hours/week	No	NA
#7	Shoulder	Doctor	M	36-45	Caucasian	Systems Engineer	Bachelor's	Over 6 months	Over 2 hours/week	Yes	MD, Books, Web, People
#8	Arthritis	Doctor	F	46-60	African American	Legal Instrument Examiner	Bachelor's	Over 6 months	Over 2 hours/week	Yes	MD, Web, People

P = Participant   MD=Doctor   People=People with similar problem   Groups=Support groups   CH=Clearinghouse

Demographics of Focus Group II

P	Health Problem	Method of Diagnosis	Gender	Age Group	Race Ethnic Group	Occupation	Education	E-mail experience	Web experience	Previously looked for health information about problem	Methods used to look for health information
#1	Fibromyalgia	Doctor	F	46-60	Caucasian	Retired	Bachelor's	Over 6 months	Over 2 hours/week	Yes	MD, Books, Groups, Web, People, NIH, CH
#2	Back	Doctor	F	46-60	Caucasian	Security Guard	Bachelor's	Over 6 months	Over 2 hours/week	Yes	MD, Books, Web, People, NIH
#3	Arthritis	Doctor	F	46-60	African American	Administrative Coordinator	Some college	Over 6 months	Over 2 hours/week	Yes	MD, Web, People
#4	Knee	Doctor	M	18-24	Caucasian	Marketing	Bachelor's	Over 6 months	Over 2 hours/week	Yes	MD, Web, People
#5	Shoulder	Doctor	M	25-35	Caucasian	Computer Specialist	Bachelor's	Over 6 months	Over 2 hours/week	Yes	MD, Books, Web, People, NIH, CH
#6	Arthritis	Doctor	M	Over 60	Caucasian	Retired	Beyond Bachelor's	Over 6 months	Less than 2 hours/week	Yes	MD, Books
#7	Bursitis & Rosacea	Self & Doctor	M	46-60	Caucasian	Program Analyst	Beyond Bachelor's	Over 6 months	Over 2 hours/week	Yes	MD, Web, People
#8	Back	Doctor	M	46-60	African American	Teacher	Beyond Bachelor's	Over 6 months	Less than 2 hours/week	Yes	MD, Books, Groups, People, CH

P = Participant   MD=Doctor   People=People with similar problem   Groups=Support groups   CH=Clearinghouse

Appendix I
Video Release Form for Focus Groups

Video Release Form

Video recordings made during this study will be used for research and development. Therefore, I understand that my focus group will be recorded and viewed by the staff of UserWorks and their client. I further understand that UserWorks or their client may wish to use segments of these recordings to illustrate presentations offered to professional audiences.

I also understand that the information discussed in this session is confidential, and I will not disclose any of the information discussed to anyone not affiliated with this study.

I, _____, freely and voluntarily consent to participate in a focus group.   I understand that my participation in this group is completely voluntary. I also understand that I may withdraw my consent and discontinue my participation at any time without penalty or prejudice to me.

I have read and understood the foregoing and understand that I may receive a copy of this form, upon request, on the day of the focus group.

Participant's Signature: _____**Date:** _____

Appendix J
Focus Group Questionnaire Responses

Responses from Focus Group 1 to questionnaire self-administered on day of study

	Prior contact with a health CH	Knew about NIAMS CH before study	Medical condition asked about through NIAMS CH	Length of timing living with medical condition	Specific question asked of NIAMS CH	Method(s) used to contact CH	Personal level of knowledge about medical condition 1 low/7 high	Personal satisfaction with information from NIAMS CH 1 low/7 high
P1	No	No	Osteoporosis	4 years	(no comment)	E-mail	4	NA Did not receive info.
P2	Yes, Dr. Mirken, Herbal Fitness	No	High blood pressure, diabetes, nutrition	42 years	About natural remedies and preventive remedies.	Telephone & Web site	5	5
P3	No	No	Arthritis	3 years	Information on arthritis.	Telephone	5	NA Did not receive info.
P4	No	No	Eczema	Approx. 7 years	None, only asked to have information sent to me in the mail.	Telephone	3	5
P5	No	No	Back related problems	25 years	Asked for information	Web site	3	NA Received info but did not have time to evaluate it.
P6	No	No	Arthritis	10 years	General information requested on arthritis.	Telephone	4	7
P 7	Yes, NIAMS	No	Shoulder problems	Little over 1 year	Concerning tendonopathy, bursitis, and treatment options.	Telephone & Web site	4	5
P 8	No	No	Arthritis remedies	Approx. 5 years	For information related to arthritis.	Telephone	4	1

Responses from Focus Group 2 to questionnaire self-administered on day of study

	Prior contact with a health CH	Knew about NIAMS CH before study	Medical condition asked about through NIAMS CH	Length of timing living with medical condition	Specific question asked of NIAMS CH	Method(s) used to contact CH	Personal level of knowledge about medical condition	Personal satisfaction with information from NIAMS CH
P1	Yes, not sure where	No	Fibromyalgia	30 years without explanation; diagnosed over 4 years	Requested info on fibromyalgia.	E-mail & Web site	7	4
P2	No	No	Lower back pain	7 years on and off	Re: stiffness and pain in lower back and leg, told them I had surgery before.	E-mail	6	5
P3	No	No	Arthritis	4-5 years	My fingers are beginning to get a slight curve in the joint area and I was wondering if this could be arrested or reversed.	E-mail	2	NA Did not receive info.
P4	No	No	Knee replacement	About 10 years	For info on knee replacement, no specific question.	Web site	5	NA Did not receive info.
P5	No	Yes, I work for a Div. of NIH	Shoulder injury	3 years	I asked for general information regarding my injury and where to get more information.	E-mail & Web site.	4	5
P6	No	No	Osteoarthritis	2 years	Will my condition worsen over time? What exactly is happening?	Telephone	3	1 Never arrived by 3/25. Called 3/14.
P7	No	No	Rosacea, joint inflammation, arthritis	10 years-rosacea; 2 years-inflammation	I asked for info. I asked no specific question.	Web site	5	NA Haven't yet received info.
P8	No	No	Info on replacement disk	32 years	About replacement disc or any info on correction of such a problem.	Telephone	6	3 Did not receive the info.

Appendix K
Script for Focus Groups

NIAMS Clearinghouse Evaluation

Focus Group Script

March 25 & 26, 2002

I.   Introductions (10 min.)

Facilitator introduction

Participant self-introduction and "break the ice" question

How would you rather be spending the afternoon (or evening), if you were not participating in this focus group?

II. Interacting with the NIAMS Clearinghouse (30 min.)

1. Describe the process you went through requesting information or asking a question of the Clearinghouse and how you feel about your experience?

(Facilitator completes chart)

Table 1. Summary of participants' contact with the NIAMS Clearinghouse (CH)

Type of contact	Participant #	Characteristics +	Characteristics −	Overall grade for CH
Phone (spoke directly with CH staff)				

Phone (left message for CH)				
E-mail (sent to or received from CH)				
Web site				

2.   What about the overall customer service? Based on your interaction with the Clearinghouse, how do you feel about the level of customer service?

3.   If you used the Web site, how "user-friendly" was the experience?

4.   What might have been missing from the interaction that you would have expected?

5.   What changes would you suggest to the process of interacting with the Clearinghouse?

8.   As a consumer, how satisfied do you feel about interacting with the Clearinghouse?

9.   As a group, what letter grade would you assign overall to interacting with the Clearinghouse based on the experiences we've talked about?

III. Evaluating information received from the Clearinghouse (20 min.)

10. Tell me what information you requested or the question you posed to the Clearinghouse?

11. Please take out the information that you received from the Clearinghouse. Did anyone not receive information or did not bring the information with them? *(If Facilitator passes out information to those participants who have none.)*
Please select one item, if you received more the one piece of material, and put the other items aside. I would like you to spend the next 5 minutes reviewing the item you selected and completing this questionnaire. Please be sure to write on the questionnaire your participant number and the title of the item you are reviewing.

12. *(After 5 minutes, ask each person to talk about the item he or she reviewed.)* **Briefly describe the information you received including your comments from the questionnaire.**

    a. **What is the purpose of this publication?**

    b. **Who is the intended audience?**

    c. **How appealing is this publication to you?**

    d. **How do you feel about the type size, the graphics, and the page design?**

    e. **What's your impression about how well the information is organized?**

    f. **How understandable do you find this information?**

    g. **How usable do you find this information?**

h. What improvements do feel are needed?

13. How did this information meet, exceed, or fall short of your expectations?

14. What, if anything, was missing that you would have expected in the information or answer that you received?

15.   How appropriate was the information for you, personally, in meeting your health-related needs?

IV. Receiving information from the NIAMS Clearinghouse (10 min.)

16. How long did it take for you to receive the information you wanted or a response to your question? *(If someone did not receive information, although they requested it, ask when he or she contacted the Clearinghouse and method used.)*

17. How do you feel about the amount of time it took?

18. What other comments do you have about the process of receiving or retrieving information or having your question answered?

V. Evaluating Clearinghouse publications

The group will review and evaluate two types of Clearinghouse publications—"Questions and Answers" and "Handout on Health." The group will review and evaluate one type of publication before moving onto the next type of publication. The facilitator will distribute a publication and questionnaire to each participant. Each participant will have 5 minutes to review the publication (without discussion) and to answer the questionnaire. Following the review the group will spend 10 minutes discussing the publication.

19. Discussion about "Questions and Answers"

    a. What is the purpose of this publication?

    b. Who is the intended audience?

    c. How appealing is this publication to you?

    d. How do you feel about the type size, the graphics, and the page design?

    e. What's your impression about how well the information is organized?

    f. How understandable do you find this information?

    g. How usable do you find this information?

h. What improvements do feel are needed?

20. Discussion about "Handout on Health"

    a. **What is the purpose of this publication?**

    b. **Who is the intended audience?**

    c. **How appealing is this publication to you?**

    d. **How do you feel about the type size, the graphics, and the page design?**

    e. **What's your impression about how well the information is organized?**

    f. **How understandable do you find this information?**

    g. **How usable do you find this information?**

h. What improvements do feel are needed?

VI.   Evaluating NIAMS Web site (10 min.)

The home page of the NIAMS Web site will be projected on the wall and the facilitator will have control of the mouse.

21.   How many of you have seen this site before?

22.   How many of you are seeing this site for the first time?

23.   What are your reactions to the site?

24.   (After clicking on the Health Information link) *What do you think of the information on this page?*

25.   (While looking at a publication page) *Do you think the information in this publication is the same as on the Web site?*

26.   (While looking at a publication page) *How do you feel about reading this information on the Web compared to reading a booklet?*

Appendix L
Script for Follow-Up Interviews

I. Introduction

Hello, I'm _____ from UserWorks, a Maryland consulting company. Today, I'd like to talk with you about using the National Institute of Arthritis and Musculoskeletal and Skin Diseases Information Clearinghouse. This discussion should take about half an hour. You have used the NIAMS Information Clearinghouse recently, and have volunteered to talk with us about your experience, correct?

There are a few things I'd like you to remember as we talk:

- I have some specific issues that I want to cover but one of the things I don't want to do is to limit you or your opinions. Feel free to talk about any aspect of your interaction with the Clearinghouse, whether I ask about it directly or not.
- Neither UserWorks nor I are involved in the operation of the Clearinghouse. You are not going to hurt my feelings by saying that you don't like something. In fact, we have been hired to ask you about the Clearinghouse and give NIAMS feedback about your responses. So, the only thing you could do that would be a problem is if you were not candid in your opinions.
- We would like to audiotape this conversation so that we are sure to get our notes correct. Do we have your permission to continue taping?
- Remember that everything that you say in this conversation is confidential in the sense that your name will not be associated with the information that you provide for us. When we write our report, your information will only be used in combination with other information that we have gotten from a number of other interviews, questionnaires, and comment forms that other people have completed about the NIAMS Information Clearinghouse.

Do you have any questions before we begin?

II. Discovering the NIAMS Information Clearinghouse

How many times have you contacted the NIAMS Information Clearinghouse?

Over what period of time have you been a NIAMS Information Clearinghouse user?

How did you first find out about the NIAMS Information Clearinghouse?

III. Describe contact with NIAMS Information Clearinghouse

How do you use the NIAMS Information Clearinghouse?
      How do you make contact?
      Do you ever use other methods rather than your usual one?
Is there anything confusing about making contact with the NIAMS Information Clearinghouse?

How does the NIAMS Information Clearinghouse seem to work?
      After you contact them. (phone, mail, Email, FAX, Web etc.)
      What do you think happens next at the Clearinghouse? (before any material arrives comes to you)
      Is there anything confusing about this part of the process?

Is there anything you would like to change about how things work?

Is there anything you would like to add to the Clearinghouse process?

Were you satisfied with your interaction with the Clearinghouse?

IV. Response Received

After the NIAMS Information Clearinghouse has done its work, did you receive material from the Clearinghouse?

What did you think about the people that answered your phone call, email, or letter? Were they helpful and courteous?

How long did it take for an order to arrive? Is this about right? Too long? Amazingly rapid?

For those of you who did not receive material from the NIAMS Information Clearinghouse, what happened next, if anything?

[If not mentioned before] Have any of you ever used the Web to access NIAMS Information Clearinghouse? Did you realize that the material on the NIAMS Web site was from the NIAMS Information Clearinghouse?
      Exactly what did you do?
      Did you find everything you wanted?
      Were there any problems with using the Web?

V. Information Appropriateness

When the information came from the NIAMS Information Clearinghouse, was it what you expected? Did it meet, exceed, or fall short of your expectation?

Was it appropriate for your needs? Why or why not?

VI. Information Content

What publications, if any, have you received?

    For you:

        What seemed to be the purpose of this publication?
        Who is apparently the intended audience?
        Is the design attractive?
        Is the format appropriate? [the way it is laid out on the page, use of illustrations, size of text,]
        Is the content understandable? Can you give examples?
        Can you think of anything that would improve the publication?
        Would you use this publication? Why or why not?

If the user came to NIAMS through the NIAMS Web Site:

        Where would you go on the site to find the information you were looking for?
        Was it easy to find where to go?
        Do you read publications? Print our publications?
        Was it easy to see how you would order a specific publication?
        Would you use the Web site again? Why or why not?
        Is there anything that you could suggest that would improve the site so it would be easier to use?

VII. Wrap Up and Thank You

That's all we have for you today. Thanks so much for talking with us. We really appreciate your help.