



BOLD
THINKERS
DRIVING
REAL-WORLD
IMPACT

**Support for
Evaluation Activities
Led by the National
Institute on Aging's
Office of
Communications and
Public Liaison**

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Prepared for:
Megan Homer
Freddi Karp
Office of Communications and
Public Liaison
National Institute on Aging

Submitted by:
Jessie Gerteis, MPH
Tana Brown
Abt Associates Inc.
55 Wheeler Street
Cambridge, MA 02138

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Executive Summary

The National Institute on Aging's (NIA) Office of Communications and Public Liaison (OCPL) contracted with Abt Associates to hold a series of focus groups in order to gain a better understanding about how NIA can effectively reach the informal caregivers of seniors with online health and aging information. This report provides information about the study participants, including their caregiving and information seeking behaviors; describes key findings from the focus group discussions; and offers some recommendations for improving the website's accessibility to, and visibility among, informal caregivers.

Some of the key findings discussed in greater detail in the body of this report include the following:

- Participants mainly searched the internet for specific health and disease topics, rather than general health and aging information. They reported primarily using a search engine like Google to locate health information online and relied on a few trusted websites, such as WebMD. Participants also used the websites of their health insurance carrier, hospital, healthcare provider, or of disease specific foundations and support groups.
- The majority of participants liked the NIA website. They thought it was trustworthy, had accurate and comprehensive information, was written in a way that was easy to understand, and was visually appealing and easy to navigate. Most planned to use the site to find information for their elderly loved one or themselves in the future.
- Some participants, however, felt the amount of information presented on the website and the navigation was overwhelming. A few participants felt the site was too high level for them, and thought it was more geared towards professionals than caregivers.
- Participants wanted to see information summarized into bulleted lists or tables that are easy to print and share via email. They reported that they want to be able to read full publications or reports for detailed information on topics of particular interest, but want to be presented with less text upfront and be given the option to click a link to read more.
- Participants reported that they receive the majority of their health information from healthcare professionals, and that this is their most trusted source of information.

The NIA may want to consider making some changes to their website to make it more accessible and user friendly for caregivers. This includes revising some key terminology used on the site to be more appealing for this audience, adding topic summaries, and limiting the amount of text presented on each page. The NIA may also want to consider developing partnerships with provider professional associations and other key senior organizations in order to raise awareness of the NIA website with informal caregivers.

1. Introduction and Background

The National Institute on Aging's (NIA) Office of Communications and Public Liaison (OCPL) is responsible for translating the Institute's health and aging information into user-friendly materials for the public, researchers and health professionals. As standard practice for disseminating information shifts from print materials to online information, OCPL must also shift their dissemination efforts to their website as a primary tool for sharing information with all audiences. Ensuring that seniors are reached through online resources poses some challenges, however, since seniors are less likely than younger people to use the internet.^{1,2} Informal caregivers including younger family members, friends and neighbors often serve as "information intermediaries" for seniors, looking up information online for them. In fact, according to a report recently put out by the Pew Research Center, 59% of all Americans have looked online for health information within the past year, and half of these searches were conducted on behalf of someone else.³ Therefore, targeting informal caregivers may be an effective way for NIA/OCPL to reach seniors with online resources.

NIA/OCPL contracted with Abt Associates to hold a series of focus groups with the informal caregivers of seniors to gain a better understanding about how NIA can effectively reach these information intermediaries with online information. More specifically, NIA/OCPL hoped information gathered through these focus groups would help to:

- Determine approaches for more effectively raising awareness of NIA's free health and aging online information resources, especially among informal caregivers.
- Determine if informal caregivers view NIA's online resources as accessible, trustworthy and useful for communicating health and aging information with older family members or friends.
- Determine if OCPL's current outlets for outreach activities correspond with where informal caregivers look for health and aging-related information for their elder family and friends.

This report outlines the methods used for data collection, information about the participants, key findings from the focus groups, and recommendations based on these findings that NIA can use to reach this key audience.

¹ Pew Research Center's Internet & American Life Project (2013). Demographics of Internet Users. Retrieved from <http://www.pewinternet.org/Static-Pages/Trend-Data-%28Adults%29/Whos-Online.aspx>

² European Travel Commission New Media Trend Watch (2013). USA Demographics. Retrieved from <http://www.newmediatrendwatch.com/markets-by-country/17-usa/123-demographics?start=1>

³ Pew Research Center's Internet & American Life Project (2013). Health Online 2013. Retrieved from <http://pewinternet.org/Reports/2013/Health-online.aspx>

2. Data Collection Methodology

Abt Associates conducted four focus groups with people who regularly use the Internet to help an elderly friend or family member find health information. Two groups were held in a suburb of Boston, MA and two groups were held in a suburb of St. Louis, MO. The research team selected these two locations from distinctly different regions of the United States to ensure that the responses were not specific to any one particular geographical area. Participants were also recruited to represent a diverse mix of education, race/ethnicity, and gender.

Groups were held in professional focus group facilities and participants were recruited by the facility staff, based on criteria specified by the research team. (The full set of screening questions used to select participants is included in Appendix A). Prior to attending the group discussion, participants were asked to spend some time reviewing the NIA website. (The letter the facilities sent to participants with the “pre-work” assignment is included in Appendix B). Focus groups were approximately one hour long and those who attended were given \$50 for their time and travel costs.

Each participant signed a consent form that stated that their participation was voluntary. Participants were reminded that they were not required to answer any questions at the beginning of each focus group. Participants were also asked to complete a questionnaire to provide specifics about their caregiving and their health information seeking behaviors. Information collected from these questionnaires is summarized in Section 2 below, and the full questionnaire is included in Appendix C.

The same staff person from Abt Associates moderated all four focus groups, and a staff person from NIA/OCPL observed all groups. The order in which questions were asked was modified between the Boston and St. Louis groups to improve the flow of the discussion; however, the same questions were presented to all groups for discussion. (The full moderator's guide is included in Appendix D).

3. Participant Information

The focus group facility staff recruited a total of 11 participants per group (a total of 44). Of the 44 people recruited, a total of 32 people participated in these group discussions. This section summarizes information collected at the time participants were recruited and from the questionnaire participants completed regarding their caregiving and online health information seeking behaviors. It should be noted that seven participants from Boston did not complete the questionnaire prior to the groups, as planned. The facility was able to follow-up and collect information from three participants, but was unable to reach the remaining four. As a result, questionnaire information was collected from a total of 28 participants.

3.1 Overview of Focus Group Participants

Groups were recruited to represent a mix of races and education levels. Participants were able to check more than one descriptor to indicate their race. Overall, 19 participants identified themselves as “White/Caucasian,” 11 as “Black/African-American,” one as “mixed race” and one as “Other.” Two participants reported their ethnicity as “Hispanic.” Ten participants reported that they had a level of education that was “less than high school, high school or high school equivalent.” Eighteen participants had a college degree (either Associates or Bachelor’s level), and four had a post graduate degree. Participant ages ranged from 25 to 63 years (average=51.4; median=52.5). The age of the loved ones participants helped ranged from 62 to 96 years.

Figure 1. Race of Participants

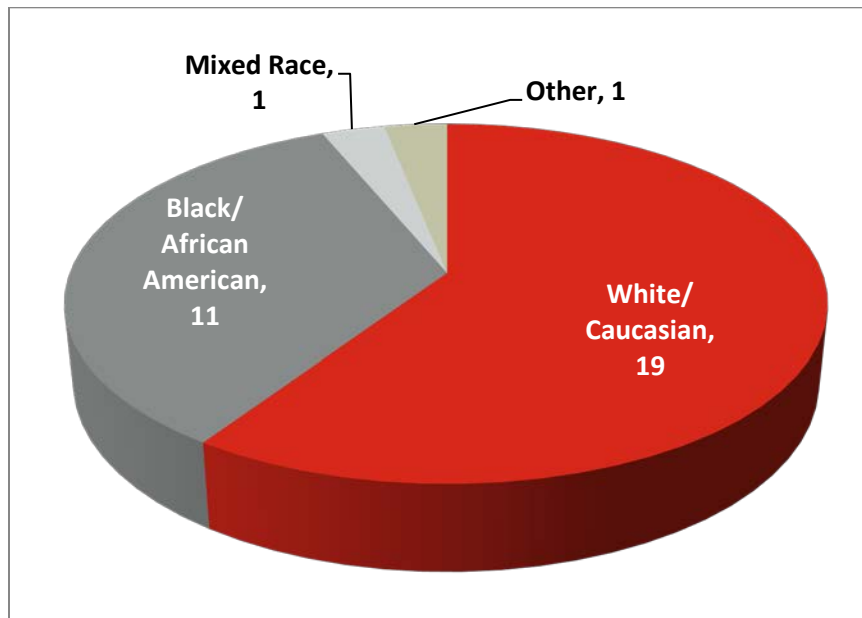
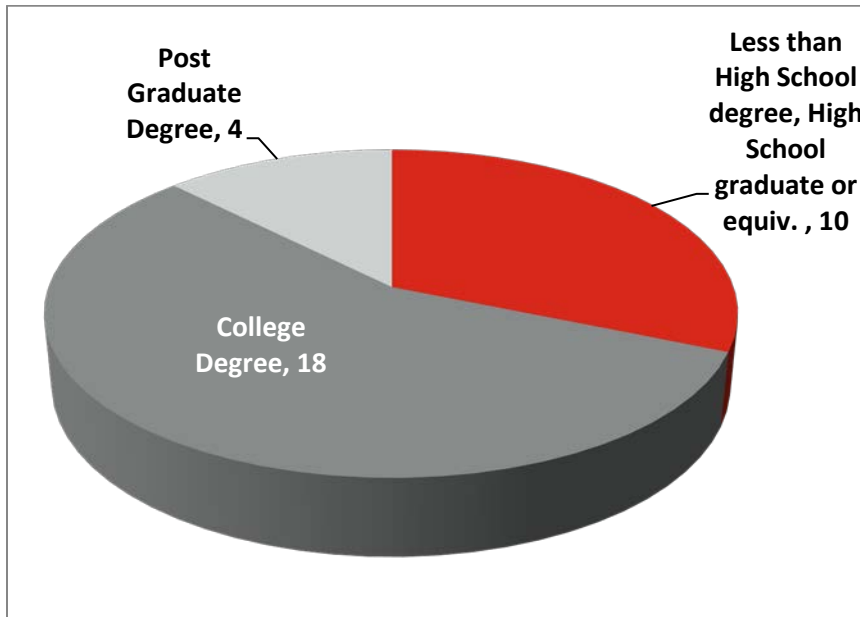


Figure 2. Education Level of Participants



The Boston participants were more highly educated (80% with either a college or post graduate degree) and White (73%), while the St. Louis participants represented more of a mix of education levels (59% with either a college or post graduate degree) and races (47% White).

Table 1 (below) displays information about the race and education level of each participant, by location and group.

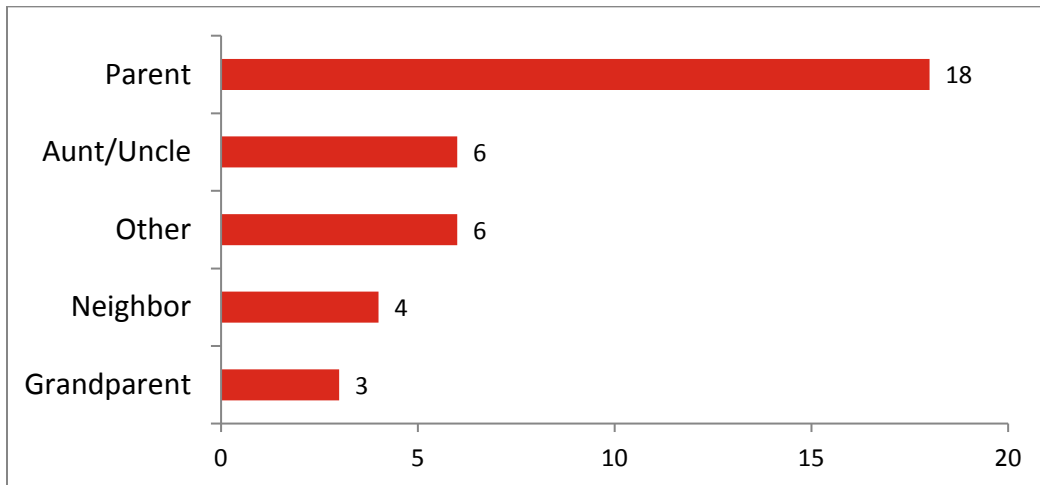
Table 1. Participants' Race and Education Level by Location and Group

Participant Number	Group Number	Race	Education level
<i>Boston</i>			
1	1	Caucasian	College Graduate
2	1	Caucasian	College Graduate
3	1	Caucasian	Less than High School/High School Equivalent
4	1	Caucasian	College Graduate
5	1	Caucasian	Less than High School/High School Equivalent
6	2	Caucasian	College Graduate
7	2	Caucasian	Less than High School/High School Equivalent
8	2	Caucasian	College Graduate
9	2	African American	Post-Graduate
10	2	African American	College Graduate
11	2	African American	College Graduate
12	2	Caucasian	College Graduate
13	2	African American	College Graduate
14	2	Caucasian	College Graduate
15	2	Caucasian	College Graduate
<i>St. Louis</i>			
16	3	Caucasian	Post-Graduate
17	3	Caucasian	Less than High School/High School Equivalent
18	3	Other	College Graduate
19	3	African American	College Graduate
20	3	African American	Less than High School/High School Equivalent
21	3	African American	College Graduate
22	3	African American	College Graduate
23	3	Mixed Race	Less than High School/High School Equivalent
24	3	African American	Post-Graduate
25	3	Caucasian	College Graduate
26	4	Caucasian	Less than High School/High School Equivalent
27	4	Caucasian	College Graduate
28	4	African American	Less than High School/High School Equivalent
29	4	Caucasian	Post-Graduate
30	4	Caucasian	College Graduate
31	4	Caucasian	Less than High School/High School Equivalent
32	4	African American	Less than High School/High School Equivalent

3.2 Caregiving Information and Health Information Seeking Behavior

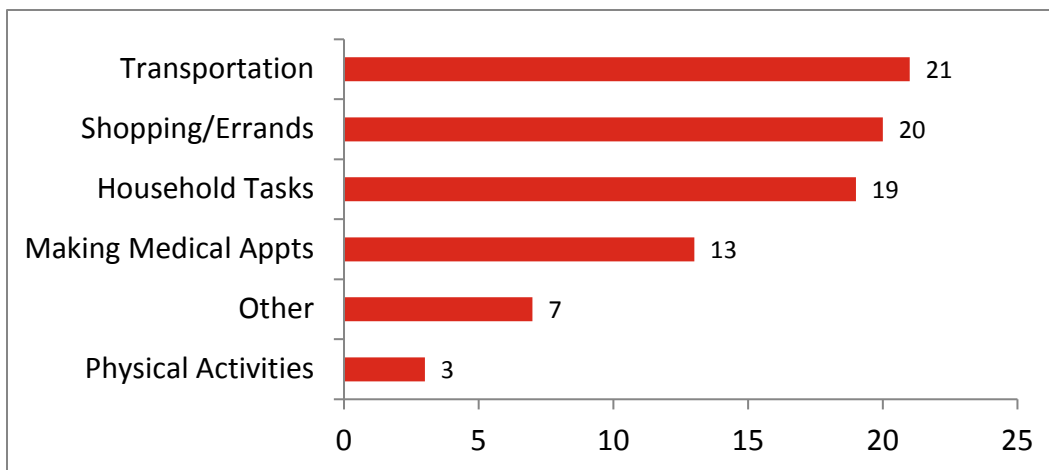
Eighteen of the participants reported that they assist a parent with finding health information; six reported assisting an aunt or uncle, and four reporting helping a neighbor, and three a grandparent. Others reported helping brothers or sisters, parents-in-law, and elderly friends. Interestingly, five participants reported helping more than one person find health information, and one person reported helping as many as six people with this task. Within the past year, twelve participants reported spending more than 10 hours searching for and reviewing health and aging information for their elderly loved one(s), eight participants reported spending between one and three hours, and seven participants reported spending between four and 10 hours.

Figure 3. Who Participants Help Find Health Information



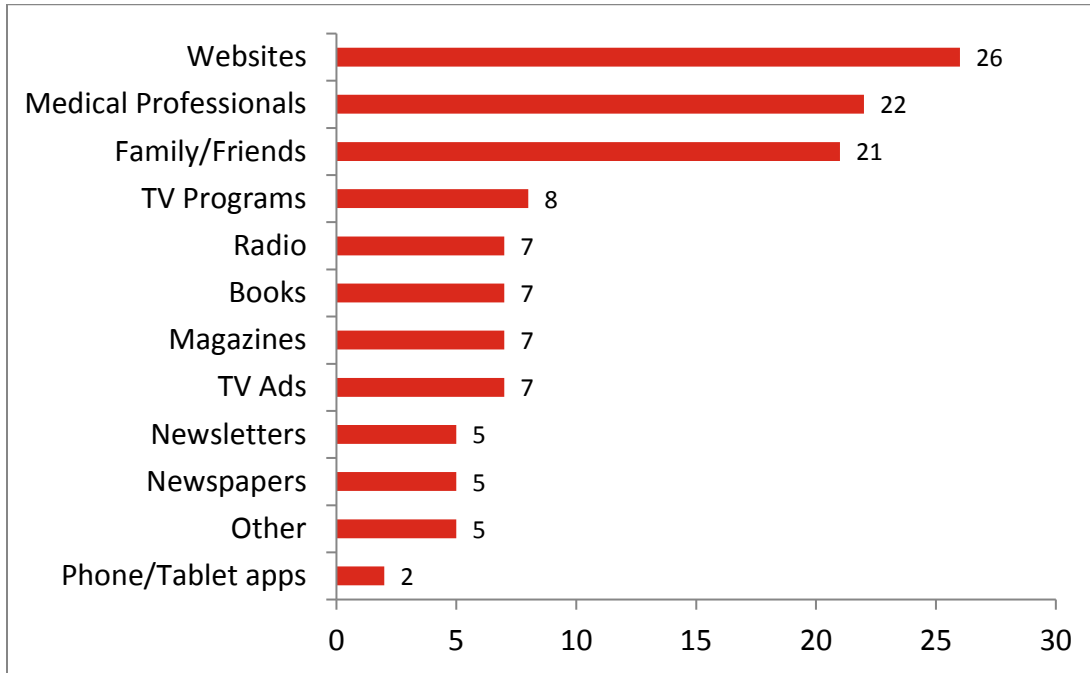
All but one participant reported helping their elderly friend/family member with other tasks in addition to searching for online health information. Many participants reported helping with, transportation (21), grocery shopping or other errands (20), and household tasks (19). Roughly half of the participants (13) indicated that they help schedule medical appointments. Only four participants reported living with their elderly loved one, and only three helped with physical activities.

Figure 4. How Participants Assist Their Elderly Loved One



All focus group participants reported having access to a computer with high-speed internet access at home. Aside from websites (26), participants most frequently noted medical professionals (22) and family/friends (21) as their source for health information. Participants also cited television programs (8) and advertisements (7) as sources of health information. Several participants reported finding health information in magazines (7), on the radio (7), and in books (7).

Figure 5. Participants' Sources for Health Information



The group was almost evenly divided among those who use either a smart phone and/or a tablet to view online information (15 yes, 13 no). However, only two participants indicated that they use an application on their smart phone to get health related information, and no participants reported using tablet applications for this purpose. While applications are not necessary for viewing online information on a smartphone or tablet, they often offer formatting to improve the viewing experience.

Participants were also asked about their familiarity with the National Institutes of Health (NIH) and NIA. Eighteen participants reported that they had heard of either the NIH or the NIA before they were invited to participate in this group, while ten participants had heard of neither.

4. Research Findings

Key findings from the focus groups are described in this section. We report primarily on the themes that arose across participants and groups. In some cases, however, we discuss points made by only one or two participants when these seem particularly important or insightful. This section is broken into the following thematic areas: General Online Health Information Seeking, Feedback about the NIA Website, Website Formatting Preferences, and Outreach to Caregivers.

4.1 General Online Health Information Seeking

- The majority of participants reported that they primarily look online for information about a specific health topic, disease, or condition for their elderly loved one, rather than for more general health or aging information. For example, participants reported mainly looking for information about a new diagnosis or medication and for physician reviews or health insurance coverage information.

“Usually, when I am searching, I’m looking for specific things. I’m looking for reviews on specific drugs, side effects, looking up surgeries, etc.” – Participant from Boston, group 2

“My Grandfather is popping 10-20 pills a day, so I’m Google searching, looking up reactions and side effects.” – Participant from St. Louis, group 1

- A few participants mentioned that it can be hard to find general health and aging information online, and that this is why they are less likely to search for it, not because they are not interested in this type of information.

“When you have a specific topic to zero in on it is easier to find information.” – Participant from Boston, group 2

“There’s a void of general wellness information for seniors not related to a specific illness.”
– Another participant from Boston, group 2

- Most participants reported that they use a search engine, such as Google, when they first search for health information online. Then, they either choose the website that appears to most closely align with the information they are looking for, the websites that show up at the top of their search, or the most trusted websites that show up in their search results.

“I’m not that computer savvy, so I like Google because it takes me right where I want to go. I just pick the top thing that pops up.” – Participant from St. Louis, group 2

- WebMD was often cited by participants as a primary source for online health information. While participants reported trusting the information they found on WebMD and liking the format of the website, they also pointed out that the site could lead the user to assume the worst case scenario in terms of diagnosis or outcomes.

“WebMD is a little alarmist, it isn’t reassuring.” – Participant from Boston, group 2

“Everyone goes to WebMD, and everyone walks away from WebMD sick.” – Participant from St. Louis, group 2

- A few participants reported that they use the Dr. Oz website to find health information or Angie’s List to find a new doctor. Hospital or healthcare provider websites (e.g., the Mayo Clinic), health

insurance websites (e.g., Medicare.gov, VA), disease specific foundation websites (e.g., Alzheimer's Foundation of America), and support group sites were also mentioned as places where participants search for online health information for their elderly loved ones. In addition, the following websites were mentioned by participants: Real Age, PubMed, About.com, Wikipedia, and Cancer Compass.

- Participants reported sharing information with their elderly loved ones in a variety of ways, including summarizing the information they found online, printing out information to share, sending information through email, and conducting online searches together.

"I have to read [health information] to my mom, so I print it out first." – Participant from Boston, group 2

"I first call [my in-laws], then tell them what I found online and then I forward a piece of it or the link for them to look at. But I set the groundwork first by explaining what I found, to give them some context." – Another participant from, Boston, group 2

"I print things to give to my dad, because he is more comfortable with the hard copy. If he is having a reaction to something, then we will look it up together online. If I show him the source then it is more reliable." – Participant from St. Louis, group 1

- While there were some participants who used their smart phone to search for online health information occasionally (e.g., looking up a new medication while in the doctor's office), most participants said they did not use their phone to look for health information because they find it is too difficult to read/navigate websites on such a small screen. Only a few participants reported having tablets, but those who did, said they used them to search for information online.

"The iPhone is so small. When I am looking for a lot of details, then I'll use the computer, but if I am in a bind it is on the phone. So, it is a little bit of both." – Participant from St. Louis, group 1

"If I am in the waiting room [at the doctor's office] I will use my phone." – Another participant from St. Louis, group 1

4.2 Feedback about the NIA Website

- The majority of participants reported that they liked the NIA website. These participants felt that the site had accurate and comprehensive information that was written in a way that was easy for them to understand. They also reported that they thought the site was visually appealing and easy to navigate.

"[The NIA website content] was well written, easy to understand, and concise." – Participant from Boston, group 1

"[The NIA website] is more complete because if you want to see something in particular, everything is there already; you don't have to jump around [between websites]." - Participant from St. Louis, group 1

"I liked the way it was written, good tone, informative, easy to read, not so scary like some other websites." – Participant from Boston, group 2

"It was easy to navigate, it seemed bright, and it wasn't hard to find what you're looking for." – Participant from St. Louis, group 1

- A number of participants, however, were more critical of the website. The majority of these participants expressed that the content they found on the website was good, but they were overwhelmed with the amount of information presented on the site, particularly on the home page.

“Everything is on the front page, it is too much.” – Participant from Boston, group 1

“The information itself isn’t overwhelming, but the searching on the site was because the information was just all over the place. I would rather just Google something and go right where I want rather than search through everything on this site.” – Participant from St. Louis, group 2

- A few participants felt that the website content was too high level or “intellectual” for them. These participants noted that the site seemed more geared towards professionals or researchers than to the elderly and/or caregivers. These comments came from participants with both college degrees and less than high school or high school level education. Therefore, it does not appear that this criticism was directly linked to the education level of the participant.

“There was a lot of referencing of different studies and that kind of takes people’s focus off the subject... You want to have a trusted site, but you don’t want every source cited [in the text] necessarily.” – Participant with less than high school or high school level education from St. Louis, group 2

“It seemed like it was more for researchers, professionals. It didn’t have anything on the front page that was for me.” – Participant with a college degree from St. Louis, group 2

- While overall the participants reported that the information presented on the website would be helpful for them as a caregiver, a few participants expressed confusion about the website’s target audience.

“I wasn’t sure who the main audience of the organization was. There is information for caregivers, seniors, researchers, government agencies. There are a lot of audiences, and I am not sure which section pertains to me.” – Participant from Boston, group 2

“The NIA site is trying to appeal to such a broad spectrum of people that it is overwhelming.” – Participant from St. Louis, group 2

“When I went to the publications I felt like they were for the medical community, not me.”
– Participant from Boston, group 2

- A few participants reported that they tried to use the search function of the NIA website to find particular information and were frustrated when they could not find it. Parkinson’s disease, information about particular types of cancer, how to rent medical equipment, information about colonoscopies, and how to apply for financial hardship assistance for medical care were noted as information the participants tried to find on the site but could not. (Note: One of the suggested activities in the “pre-work” letter was for participants to look up a topic of interest. See Appendix B for the pre-work assignment letter.)

“I typed in Parkinson’s and it didn’t take me anywhere.” – Participant from St. Louis, group 2

“I looked up a certain type of cancer, but I didn’t find anything.” – Participant from St. Louis, group 1

“I didn’t see information about colonoscopy there.” – Participant from St. Louis, group 1

- A few participants noted that the NIA website seemed particularly focused on Alzheimer's disease.

"I didn't spend much time on the site, but the information on Alzheimer's and dementia is very prevalent." – Participant from Boston, group 2

"Is the NIA website just for Alzheimer's?" – Participant from St. Louis, group 2

- Many participants reported that, since being introduced to NIA's website in preparation for the focus group, they had already used it to find information to share with their loved one, or they planned to use it in the future. These participants were particularly interested in using the site for information about nutrition and exercise, to find resources, and to look up information about specific diseases and medications (including information about side effects and drug interactions).

"I liked the activities section because that is something I'm trying to do with my in-laws. It showed little things to do with the grandkids, simple things to stay active, like little exercises."

– Participant from Boston, group 2

"I like the exercises. I showed them to my aunt." – Participant from St. Louis, group 1

"[The NIA website has] resource listings that were really extensive and good... I bookmarked it because I don't know when I'll need this, but I probably will." – Participant from Boston, group 1

- A number of the participants noted that they would use the website in the future to look for information for themselves, not just their elderly loved ones. This finding points to the fact that while caregivers are currently considered "information intermediaries" to reach the target audience of seniors, many caregivers are middle-aged themselves and are the future target audience for the site.

"I'll look up some information [on the NIA website] for myself. On exercise, diet, arthritis..."
– Participant from St. Louis, group 2

"The exercises, diet, health habits, sleeping, etc. [are what I like best about the site]. I want to show my friends this section." – Participant from St. Louis, group 2

- Participants reported that they found the NIA website to be trustworthy because it was from a government agency, there is no advertising on the site, the site was not a vehicle to sell products, and because of the credible way the information was written and presented.

"I prefer sites without advertising; otherwise you question the validity and wonder if they are just trying to please the advertisers. Organizations that don't accept advertising are more trustworthy." – Participant from Boston, group 2

"The government makes it seem more trustworthy." – Participant from St. Louis, group 2

"Knowing that there isn't a pharmaceutical company behind it is important." – Participant from Boston, group 1

4.3 Website Formatting Preferences

- Most participants reported that they prefer to see information presented in short summaries, bulleted lists, or tables rather than in longer publications or dense text on a page.

"Everyone wants something condensed to show their parents. You don't want to give them five pages; they just want a summary." – Participant from Boston, group 1

"I like to see a visual representation, a stepwise display of the problems and the solutions, like a matrix." – Another participant from Boston, group 1

"I like when it comes up and there are bulleted points, subjects to scan quickly and get to the information fast." – Participant from St. Louis, group 2

- A number of participants suggested that they would prefer to see a summary of information first, and then be able to click for more information if they are interested in learning more on the subject. These participants suggested that being presented with all of the information at once felt overwhelming.

"I like to see a summary with a place where you can click for more detail. That way you can go deeper if you want to, but you have the summary for a quick reference." – Participant from St. Louis, group 1

"I want to have a summary to print, but also the option to read the whole text." – Participant from Boston, group 1

"Some pages, when you opened them, were a lot of reading. I like to click for more information, to have it broken down into little pieces like WebMD. It should be condensed so you can click to read more instead of having one long page of text." – Participant from Boston, group 2

"The information has to be there, but you can have a Reader's Digest version too." – Participant from St. Louis, group 2

- Participants reported preferring when websites are designed to facilitate printing and emailing so that information can be easily shared with elderly loved ones and other family members. For example, most participants liked the idea of a "share" button to easily share information via email.

"I always prefer when there is a nice easy way [to send information in the form of an email]. Like an "easy" button for something that is meant to be sent as a document. I use it when it is available." – Participant from Boston, group 2

"If you have multiple family members like sisters and brothers, and you're the main person of contact, to be able to easily share information is huge." – Participant from Boston, group 2

- One participant recommended adding a "shopping cart" feature where a user could easily store information of interest as they continued to brows the site, so they would not need to go back to find it again when they are done. Others in the group liked this idea as well.

"You know when you are shopping online, and you can set your own shopping cart? Something like that would be good [on the NIA website]. So, while you're trying to find information for your parents, you can put it in the cart...so you don't have to go back and search for it." – Participant from St. Louis, group 1

- Participants were somewhat mixed in whether or not they liked the idea of videos as a way to see health information. Most participants reported liking videos, but some thought that videos are too time-consuming and reported that they would rather just scan the information presented in text format. In general, however, participants reported that they prefer videos that are short and are demonstrations or visual representations over "talking head" type videos.

"I would like to see little videos to see things in action, like exercises and things for balance. Videos are helpful." – Participant from St. Louis, group 2

"The only time videos are helpful is if there is an actual diagram...or some animation, something that might be explained better visually." – Participant from Boston, group 1

"Yes [I'd like to see a video on the website] if it's instructional, showing exercises, stretching, etc. Not if it's a doctor going on and on." – Participant from St. Louis, group 2

4.4 Outreach to Caregivers

- Only one of the participants reported that she had been to the NIA website prior to being asked to review it for this focus group. A number of participants expressed some frustration that they had never found the site during their online searches for health information.

"The [NIA] website is very hard to find; it doesn't come up in a Google search." – Participant from Boston, group 1

"There are things [on the NIA website] I can bring to my dad that I didn't even know were available, because I didn't know where to look." – Participant from Boston, group 2

- Most participants expressed interest in, and said they would sign up for, an electronic newsletter or listserv from NIA if it was easy to find.

- A number of people mentioned that they would want to be able to set their preferences in terms of topics of interest and frequency for emails.

"Yes, [I would like to be on an NIA listserv] but I don't want too many emails. There needs to be a way to narrow in on the information you want." – Participant from Boston, group 2

"If there was a way to set parameters to get what you want, when you want it, then that would be good." – Participant from Boston, group 2

- A few participants expressed interest in a smart phone app for the NIA site, while others said they would not use one. Those who reported that they would like an app said this was because it would help make the website more easily viewable via smart phone.

"Apps show up differently on the phone, they are formatted to be read there." – Participant from St. Louis, group 1

- In the pre-group questionnaire, participants reported receiving their health related information most often from a healthcare professional or from family or friends. Participants reported during the groups that they are more likely to trust information that came from these known and trusted sources. Participants thought that flyers distributed through doctor's offices and healthcare centers, as well as through senior centers or other senior care facilities would be the best way for NIA to reach them with information about the website.

- Google ads or Google search optimization; public service announcements or advertisements on television, radio, magazines (e.g., AARP, Newsweek), or local newspapers; and paper or electronic newsletters were also suggested as ways NIA could effectively raise awareness of their website among caregivers.

5. Recommendations

The Abt Team offers NIA the following recommendations aimed at improving the website's overall accessibility and usability for caregivers and to raise caregivers' awareness about the site. These recommendations are based on the findings from the focus group discussions.

- Change the terminology on the home page from “the Public” to “Seniors & Family Members.” These terms are more likely to resonate with users and are more closely associated with the reasons they are seeking information on the NIA website. While the NIA may think of some of their users as “the public,” it is unlikely that many users would associate this terminology with themselves or their loved one.
- Change the heading on the home page that says “Health Research for You” to “Health Information for You.” While users want to know that the information on the website is based on solid evidence, they also want to know that it has been summarized and translated in a way that will be easy for them to use and understand. Some users may worry that any information labeled with the term “research” will be too difficult for them to understand.
- Add a short summary at the top of each page about the topic described on the page, and then have more information available for those who want to read more on the topic, for example through a “read more” link. Users want to be able to quickly determine if the page contains the information in which they are most interested, and some are overwhelmed by being presented with a lot of information or text on a page.
- Create summary documents with bulleted text that provide a concise overview of each topic. While webpages can currently be easily printed on the NIA website, users want shorter summaries that they can share with their loved ones by printing or via email.
- Add a link to sign up for the electronic newsletter to the topic pages throughout the site, for example near the “printer-friendly version” and “send to friend” options. Allow users to specify a preference for the frequency of emails, or add a note that alerts will not be sent out more than once a month to allay concerns about signing up.
- Label internal website search results so that users can easily determine the category of each result (e.g., “publication,” “press release,” “funding announcement”). Keep the results ordered by relevancy to the search terms, but label each result with its category type. This will make it easier for users to quickly scan the list of results and determine which items most closely align with his or her personal interests/needs.
- Work with professional associations that represent healthcare providers and other key organizations that work with seniors to promote the resources available through the NIA website. These groups have existing networks of professionals working in the field directly with seniors and caregivers, and these existing relationships can be leveraged to disseminate information about the NIA website to these target audiences. Consider outreach to the following groups: American Academy of Family Physicians, American Medical Association, American College of Physicians, Society of General Internal Medicine, American Geriatrics Society, American Academy of Nurse Practitioners, American Nurses Association, American Academy of Physician Assistants, and the National Council on Aging and American Society on Aging.

- Consider developing short videos to visually illustrate specific topics covered on the website. These videos would be particularly beneficial for topics that can be better explained with a visual depiction rather than written description (for example, the proper form for recommended exercises).
- Consider developing a “shopping cart” feature that would allow users to store information of interest as they browse the site. This feature would allow users to easily email or print these documents together when they are done reviewing the website. Alternatively (or additionally) consider adding a “bookmark” feature so that users could easily come back to parts of the website they want to read more about later, or want to share with a loved one at a later time.

6. Study Limitations and Lessons Learned

In this section we discuss the limitations of this research project as well as some of the key lessons that were learned by the study team through the process of conducting this work.

6.1 Study Limitations

The findings from this project should be considered in light of the limitations described below.

- In general, qualitative research relies on small, non-representative samples and therefore cannot be generalized to a larger population.
- Due to the limited budget for this project we were able to hold only four focus groups across two geographic locations. While the research team feels confident that the findings from this limited number of participants are meaningful, holding additional groups in more locations may have resulted in additional insights.
- We made efforts to recruit groups that were mixed in terms of both race/ethnicity and education level. We were able to achieve a mix of participants in both of these areas, however, the majority of participants were white and college educated. This was particularly true for the groups in Boston, which were less diverse than the groups in St. Louis.
 - Because groups were mixed by race and education level, it is possible that some differences between these groups were obscured. For example, separating the focus groups by education level might have revealed differential preferences about the website that participants did not feel comfortable raising in the combined group discussions.
- This project was meant to elicit participants' general online health information searching behaviors and preferences as well as their overall reactions to, and impressions about, the NIA website. For this reason, we asked participants to review the site prior to attending the groups and did not provide access to the websites during the groups. This meant that participants spent varying amounts of time reviewing the website, with some spending a considerable amount of time and thought on this task and others spending very little or no time on the site prior to the group. In addition, all participants were required to rely on their memory of the website to answer questions during the group (e.g., what features they liked most).

6.2 Lessons Learned

There were a number of lessons that the research team learned during the implementation of this project that may be helpful for future NIA research projects. These lessons are described below.

- We originally explored the idea of using community organizations to recruit participants and host the focus groups; however, it became apparent that this option would not be significantly less expensive than using professional focus group facilities because additional staff time would be required to identify appropriate organizations and assist with recruitment efforts. Additionally, the research team would have had less control over the type of participants recruited, and it was not clear that the community organizations would have been able to recruit an adequate number of informal caregivers that met the recruitment specification to participate in the group discussions.

- Focus group facilities offer a number of professional services to assist with effective and efficient focus group recruitment and facilitation, which often makes the expense worthwhile. Facilities maintain large databases of prospective participants and are therefore able to quickly recruit participants that meet a number of specifications. When recruited participants cancel, facilities are able to replace them. Focus group facility staff persons are trained to professionally screen participants to ensure they meet study specifications. Additionally, focus group facilities help facilitate high quality audio recordings of group discussions, which allows researchers to review notes for report writing purposes. Focus group facility staff also assist with collecting needed signatures for consent forms and with distributing incentive payments.
- Offering an incentive payment to compensate participants for their time and travel costs helps to achieve good show rates for focus groups. This is particularly important when you are recruiting working aged people who have many competing demands for their time.
- When conducting focus groups with working aged participants, groups are more likely to be attended if they are scheduled after work hours. Therefore, only two one-hour focus groups can be held per day in the evening hours when working with this population.
- We learned that it is harder to recruit participants in the Baltimore/Bethesda/Washington DC area, particularly with modest incentive amounts. This is likely because so many focus groups are held in this area for local federal agencies.
- We asked the focus group facilities to distribute and collect questionnaires from participants prior to the groups in addition to the required consent form. This step was missed in the Boston facility for a number of participants who arrived late for the first focus group. Since the collection of additional information is not a standard step for focus group facility staff, it became clear that it is necessary to remind them prior to all groups that the collection of this information is essential (although not mandatory), and that participants should be asked to return the completed questionnaire prior to receiving their incentive payment. While we did not utilize it for this project, providing the focus group facility with a check-off sheet may help ensure that this step isn't missed and that this data is successfully collected at the time the groups take place.

7. Future Research Directions

This research project indicated some areas of inquiry that NIA may want to consider exploring in future research projects. A few ideas for future research projects are described below.

- Website usability testing could be conducted to better understand how informal caregivers actually use the NIA website; to determine what parts of the site they are most interested in, or are confused by; and to find out if they have difficulty using the site as intended. In usability testing, participants are asked to directly engage with the website while the interviewer observes and asks questions. This allows the researchers to observe how participants directly interact with the site and to obtain the participant's immediate feedback about the site, rather than relying on their memory. The researchers can ask the participants to describe or explain parts of the website or how they are using it in order to gain a better understanding of how they are interpreting (or misinterpreting) the information presented and how they respond to the site. The participant can also be given short tasks (for example, to find specific information on the site), and the researcher can then observe how the participant engages in the activity and see if he or she encounters any difficulties.
 - Usability testing could be conducted with caregivers alone or with dyads of caregivers and seniors, which might provide additional insights into how caregivers search for information with their loved ones.
- If any changes are made to the website based on recommendations from this report, additional research could be done to determine if those changes achieve their intended goals. For example, if NIA decides to develop short, printable summaries for topics on the site, focus groups or usability testing could be used to determine if users like these and find them useful.
- Market research could be conducted to determine how beneficial it would be for NIA to develop smart phone or tablet applications for the website. For example, the use of applications by other websites that target a similar audience could be analyzed to determine how popular these applications are, and if they have attracted new users or have increased user engagement with the site.

Appendix A. Participant Recruitment Screener

[Recruiters may substitute standard introduction here]: Hello, my name is _____ and I am calling from [insert name of focus group facility]. We are calling to see if you would be willing to participate in an upcoming focus group.

[Please read]: The National Institute on Aging, part of the National Institutes of Health, is a federal agency looking for feedback from people who assist elderly friends and family members with finding information about health and aging. The aging institute would like to know about where the people go to find this information and what is of interest to the older adults.

1. Do you regularly use the internet to find information (i.e., not just for games or email)?

Yes: **[Continue.]**

No: ["Thank you for your time. Unfortunately, you do not meet the requirements for this particular project, but we may be in touch in the future about other opportunities." **End call**]

2. Would you currently identify yourself as someone who provides health information for an elderly friend or family member? You do NOT need to live in the same geographic location as this person; this help may be provided long-distance.

Yes: **[Continue.]**

No: ["Thank you for your time. Unfortunately, you do not meet the requirements for this particular project, but we may be in touch in the future about other opportunities" **End call**]

3. Have you used the internet to find health information for an elderly friend or family member at least once within the past 6 months?

Yes: **[Continue.]**

No: ["Thank you for your time. Unfortunately, you do not meet the requirements for this particular project, but we may be in touch in the future about other opportunities" **End call**]

4. Is this elderly friend or family member at least 70 years of age?

Yes: **[Continue.]**

No: ["Thank you for your time. Unfortunately, you do not meet the requirements for this particular project, but we may be in touch in the future about other opportunities" **End call**]

5. Do you communicate at least once a month with this elderly friend or family member, either in person or by phone?

Yes: **[Continue.]**

No: ["Thank you for your time. Unfortunately, you do not meet the requirements for this particular project, but we may be in touch in the future about other opportunities" **End call**]

6. What is your race? **[recruit a mix]**

Black/African American

White/Caucasian

Asian

American Indian or Alaskan Native

Native Hawaiian or Other Pacific Islander

Other

7. What is your education level? **[recruit a mix]**

Less than High School / HS grad or equivalent

College graduate (Associate's degree/Bachelor's degree)

Post-graduate degree

8. We are conducting a focus group on **[DATE]** from **[TIME]** in **[LOCATION]** with people, like you, who help find health information for elderly friends and family. Information collected during the focus group will provide guidance to the National Institute on Aging on ways to enhance their communication with caregivers. Participants will receive \$50. Are you interested in participating?

Yes: **[Continue.]**

No: ["Thank you for your time." **End call**]

[Standard facility closing and invitation]

Appendix B. Pre-work Letter

[Focus Group Facility Letterhead]

Dear [INSERT NAME OF PARTICIPANT],

Thank you for agreeing to participate in the upcoming focus group for the National Institute on Aging (NIA). Before the group, please spend about 15 minutes reviewing the Institute's website:

<http://www.nia.nih.gov/>.

Feel free to just explore areas of the site that catch your eye, or, if you'd prefer something specific, here are a couple tasks to try:

- On the "Health and Aging" section of the website, take a look at the "Caregiving" and "Healthy Aging and Longevity" sections under "Featured Health Topics."
 - Do you like how the information is organized? Do the materials seem like something you might share with your older family member or friend, or use yourself?
- Search for information about Alzheimer's disease or another health issue of interest to you.
 - Is the information you found what you expected? Do the materials seem useful?

Discussion about the NIA website will be a part of the focus group, including your feedback about what aspects of the site you find most useful and suggestions about ways it could be improved. However, the discussion will include other things as well, so it will be ok if you don't have time to review the website.

Once again, thank you for agreeing to participate in this upcoming focus group— your opinions will make an important contribution for the National Institute on Aging.

Sincerely,

[SIGNED BY REPRESENTATIVE FROM FOCUS GROUP FACILITY]

Appendix C. Participant Questionnaire

Burden Disclosure Statement

Public reporting burden for this collection of information is estimated to average 10 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 (0925-0634). Do not return the completed form to this address.

You have been invited to participate in this group because you help an elderly friend or family member find health information. Please answer a few questions about yourself and this relationship prior to our group discussion.

1. What is your relationship with the person you help find health information? Is he/she your...
 - Parent
 - Grandparent
 - Aunt/Uncle
 - Neighbor
 - Other: _____
2. How much time have you spent looking for and reviewing health and aging information for this person in the past year?
 - Less than 1 hour
 - 1-3 hours
 - 4-10 hours
 - More than 10 hours
3. In addition to help finding health information, what other help do you regularly give this person? (Check all that apply)
 - Help with household tasks (e.g., cleaning, cooking, preparing meals)
 - Transportation
 - Setting up medical appointments
 - Help with grocery shopping or other errands
 - Help with physical activities, such as getting out of bed, getting to the bathroom, bathing, etc.
 - Other _____
 - None, just assist with finding information

4. Does this person live with you?

- Yes
- No

5. Which best describes you:

- I have a home computer
- I do not have a home computer, but I have access to another computer (such as at work or at a library); I use the computer at: _____

6. Which best describes your internet access:

- Dial-up internet
- High speed internet

7. Do you use a smart phone or tablet to view online information?

- Yes
- No

8. Where do you usually get your health information? (Please check all that apply and, where indicated, please fill in specific details.)

- Online (using a computer, smart phone or tablet); Name of website(s): _____
- Television program; Name of program(s): _____
- Television advertisements
- Newspaper; Name of paper(s): _____
- Magazine; Name of magazine(s) : _____
- Newsletter; Name of newsletter(s) _____
- Radio; Name of station(s): _____
- Books
- Smart phone applications (apps, or programs); Name or description of apps: _____
- Tablet applications (apps or programs); Name or description of apps: _____
- _____
- Doctor, nurse, or other medical professional
- Family members or friends
- Other; Please explain: _____

9. Before being invited to this focus group, had you heard of the National Institute on Aging (NIA) and/or the National Institutes of Health (NIH)?

- Yes, both NIA and NIH
- Yes, just NIA
- Yes, just NIH
- No

10. What is your ethnicity?

- Hispanic or Latino
- Not Hispanic or Latino

11. What is your race? (Please check all that apply)

- Black/African American
- White/Caucasian
- Asian
- American Indian or Alaskan Native
- Native Hawaiian or Other Pacific Islander
- Other: _____

12. What is your age? _____

13. What is the age of the family member/person you find health and aging information for? _____

Appendix D. Focus Group Moderator's Guide

Introduction (1 minute)

Welcome. Thank you for joining us today. My name is Jessie, and I am from Abt Associates Inc. We do research on health care, and have been hired by the National Institute on Aging (NIA) to conduct this focus group.

The NIA, part of the National Institutes of Health, is interested to learn from these groups how their website can better serve people like you, the caregivers who help and elderly friend or family member. They know that often it is the caregivers who are the ones who are coming to the website to find health and aging information, rather than the elderly person him or herself. And they want to be sure the site is meeting your needs.

Informed Consent (2 minutes)

Before we begin, I need to read aloud some of the key points of the consent form you just signed. Did everyone sign the form?

- The focus group will last approximately 1 hour
- Your participation is voluntary: You do not have to answer any questions you do not wish to answer, and you can quit at any time.
- You will receive \$50 today for your participation
- The discussion will be confidential: A summary of the notes will be shared with NIA. Your comments, and those of others in the focus group, will be used in reports to the government, but this will be in summary form and your name will not be included in the report.
- A couple of my colleagues are behind the glass today, and will be taking notes.
- Our discussion will not be video recorded, but it will be audio recorded so that we can go back and make sure we correctly heard what you told us.

How the focus group will work (1 minute)

- This will be an informal and relaxed discussion,
- During the discussion, please feel free to ask me or each other if something is unclear
- There are no right or wrong answers
- Please feel free to tell me what you really think. I don't work for the NIA, so even if you have something critical to say about their website, it won't hurt my feelings.
- If you disagree with what someone else says, or have had a different experience, please say so, it is important for me to understand if there are differences in opinion.
- Please be respectful of each other and the opinions expressed today
- Be careful not to talk all at once; I don't want to miss anything that is said

- My job is to make sure we hear from everyone. Some people talk more than others, and I'll be encouraging everyone to speak up.

Does anyone have any questions before we begin?

Participant Introductions (7 minutes)

Let's go around the room and quickly introduce ourselves. Everyone is here because they help out an elderly friend or family member with at least finding health information, and maybe with much more. Please share with the group:

- Your first name
- Who the elderly person is who you help out (e.g., father, aunt, spouse, neighbor)

Questions

1. In the past year, what type of health information have you looked for online for your elderly friend or family member?
2. How do you usually search for health and aging related information online? For example, do you use a search engine such as Google or Bing, or do you go to certain trusted websites?
 - Probe: If you go to certain sites: which sites do you go to?
3. What are some specific examples of groups/organizations and/or websites where you have found useful health and aging information in the past?
4. What was it about these sites or the information you found there made it useful to you?
 - Probe: any sites or aspects of the sites that you found particularly NOT useful?
5. After reviewing the NIA website for this focus group, what do you think of NIA's online resources?
 - Prompt: How do NIA's online materials compare to the resources you currently share with your friend or family member? Do you find them more or less useful? Why?
 - Probe: Does the site have the type of health information you usually search for online? How easy was it to find the information you were looking for?
 - Probe: Is there anything else that you would like to see on the NIA website that isn't currently there?
6. What do you like the most about the NIA website and the materials found there? What do you like the least? Why?

7. In what format do you like to see health related information displayed on the websites you use?
 - Prompt: Do you like to find research summaries, fact sheets, tools or checklists or full publications?
 - Prompt: Do you like documents that you can easily print out?
 - Prompt: Do you use your mobile device (smart phone or tablet) to view online health information? If so, how do you use it? Do you use apps?
 - Prompt: Are you interested in short videos related health and aging information?
8. How do you generally share the information you find online with your elderly friend or family member?
 - Prompt: Do you print off information the information you have found to share it? Take notes and talk with your friend or family member? Email info or links? Sit down and do the search on the internet together? Another sharing method?
 - i. Prompt: If you print out the info, do you print everything on the topic, entire documents, or just excerpts?
 - ii. Prompt: If you email the info, do you look for an easy way to email directly from the site or do you prefer to copy and paste the information into an email?
9. Are you usually able to find the health and aging information you are looking for online? Are there health or aging materials you would like to find online, but aren't sure where to look?
 - Probe: If yes, what types of materials would you like to be able to find?
10. Had any of you here ever been to the National Institute of Aging, also known as NIA website before being asked to do so for this group?
 - If yes, why did you go to the NIA site?
11. Thinking about yourself, or people like you, how can NIA best let you know about their website, materials and services? Where or how could NIA promote their resources to let people like you know what they offer?
 - Probe: How do you currently learn about valuable sources of health information? (Through a doctor or health professionals? Television programs or ads? Newspaper or magazines? Social service or religious organizations (if so which ones)? Social media like Facebook or Twitter?)

12. After reviewing the website, does NIA seem like a trustworthy online resource for health and aging information? Why or why not?

- Probe: How do you generally determine if online health information is trustworthy?

13. If you don't already, do you think you will use NIA website in the future? Why or why not?

- Probe: What do you think you would use the NIA site for?

14. Is there anything else anyone would like to bring up today before we end our discussion?

Thank you for participating today!