Preventing Infections During Cancer Treatment:

Development of an Interactive Patient Education Website

Angela Dunbar, BS,
Health communications specialist at the Centers for Disease Control and Prevention (CDC) Foundation, Atlanta, GA

Eric Tai, MD, MS,
Medical officer at the CDC, Atlanta, GA

Danielle Beauchesne Nielsen, MPH,
Technical specialist at ICF International in Boston, MA

Sonya Shropshire, MEd, and
Senior training manager at Westat in Atlanta

Lisa C. Richardson, MD, MPH
Director of the Division of Blood Disorders at the CDC

Abstract

Despite advances in oncology care, infections from both community and healthcare settings remain a major cause of hospitalization and death among patients with cancer receiving chemotherapy. Neutropenia (low white blood cell count) is a common and potentially dangerous side effect in patients receiving chemotherapy treatments and may lead to higher risk of infection. Preventing infection during treatment can result in significant decreases in morbidity and mortality for patients with cancer. As part of the Centers for Disease Control and Prevention's (CDC's) Preventing Infections in Cancer Patients public health campaign, a public-private partnership was formed between the CDC Foundation and Amgen, Inc. The CDC's Division of Cancer Prevention and Control developed and launched an interactive website, www.PreventCancerInfections.org, designed for patients with cancer undergoing chemotherapy. The site encourages patients to complete a risk assessment for developing neutropenia during their treatment. After completing the assessment, patients receive information about how to lower the risk for infection and keep themselves healthy while receiving chemotherapy.

Keywords

neutropenia; chemotherapy; infection

Cancer remains the second most common cause of death in the United States, accounting for about one of every four deaths (American Cancer Society, 2014). With improvements in survivorship and the growth and aging of the U.S. population, the total number of people living with cancer will continue to increase (Warren, Mariotto, Meekins, Topor, & Brown, 2008). In addition, an estimated 60,000 patients with cancer are hospitalized each year in the United States for chemotherapy-induced neutropenia and, among those hospitalized, about 4,100 will die from this complication (Caggiano, Weiss, Rickert, & Linde-Zwirble, 2005). Neutropenia and subsequent infectious complications are among the most serious treatment-related toxicities of cancer treatment and result in preventable morbidity and mortality (Herbst et al., 2009; Lyman et al., 2010). Infections among immunosuppressed patients with cancer are life-threatening, with a mortality rate associated with febrile neutropenia of 2%– 21%, depending on the cancer type, type of chemotherapy, and other factors (Herbst et al., 2009; Lyman et al., 2010; Smith et al., 2006). Infections can be difficult to identify in this vulnerable population given a lack of clinical signs and symptoms from neutropenia and a decreased febrile response (Lyman et al., 2010). As a result of this difficulty, a patient's ability to recognize of the signs and symptoms of an infection is critical. Lowering the risk for developing infections is an important strategy to decrease poor outcomes (Herbst et al., 2009), and education programs for this population may help them reduce their risk. Because patients with cancer increasingly obtain health education from the Internet to find relevant information, and one in three Americans turn to the Internet to diagnose a medical condition, an online program may be an effective way to provide patients with information to prevent infections (Chou, Liu, Post, & Hesse, 2011; Fox & Duggan, 2013; Suggs & McIntyre, 2009).

To address these issues, a public-private partnership was formed between the Centers for Disease Control and Prevention (CDC) Foundation and Amgen, Inc. to help create the CDC's Preventing Infections in Cancer Patients public health campaign. As part of this partnership, the CDC's Division of Cancer Prevention and Control developed and launched an interactive website, 3 Steps Toward Preventing Infections During Cancer Treatment (www.preventcancerinfections.org). ICF International, a public health research and consulting firm, assisted with the development, launch, maintenance, and initial evaluation of the website. The site allows patients with cancer receiving chemotherapy to assess their risk for developing neutropenia during their treatment and provides them and their caregivers with information about how to recognize the signs and symptoms of an infection, what to do if these signs and symptoms occur, and steps they can take to prevent infections.

Methods

Development of the website occurred in five phases: (a) formative research; (b) website design and development of an external advisory board (EAB); (c) concept validation; (d) website development, testing, and launch; and (e) maintenance and initial evaluation activities.

Phase 1: Formative Research

As a first step, an environmental scan was conducted consisting of three components: a review of published literature; a review of gray literature (unpublished literature from relevant Internet sources); and interviews with healthcare providers, researchers, patient advocates, and developers of other online patient education tools. The purpose of the environmental scan was to identify risk factors for developing neutropenia among patients with cancer, effective infection control practices to be implemented by patients with cancer, current practices of healthcare providers on infection control and patient education, and barriers and facilitators to healthcare providers' use of an online education program for infection control with their patients. The environmental scan also identified previously developed online education programs for patients with cancer and potential challenges in the development of the programs.

Findings from the environmental scan informed the development of a logic model (www.preventcancerinfections.org/sites/default/files/LogicModel-FINAL.pdf) that guided the development and implementation of the website. The logic model was based on the understanding of information that patients and caregivers need, including awareness and knowledge about neutropenia and subsequent risk of infection, knowledge and skills about how to prevent infections, and knowledge and skills about how to quickly recognize and control infections when they do occur.

Phase 2: Website Design and Development of an External Advisory Board

Following the formative research, activities focused on website design and functionality and the creation of a risk assessment algorithm for the website. The environmental scan revealed certain factors (e.g., age, cancer type, chemotherapy regimen, the Eastern Cooperative Oncology Group performance status). The risk factors were used to develop an algorithm estimating a patient's risk for developing neutropenia while receiving chemotherapy. The algorithm determines risk by assigning scores to responses to questions related to demographic and clinical characteristics (see Figure 1). Based on the answers, respondents are placed in either a low-risk or high-risk category and, according to this classification, provided with evidence-based information to reduce their risk for developing infections during chemotherapy treatment. The messages help patients and caregivers recognize the signs and symptoms of an infection and what to do if they develop any of these signs and symptoms.

In addition, the CDC assembled an EAB representing the fields of oncology and infection control, nursing, and patient advocacy. The role of the EAB was to provide input during the development of the website and to help with its dissemination into the patient and provider community. From October 2011 to January 2012, 11 EAB members (selected by the CDC based on expertise) contributed 2–3 hours per month completing assigned tasks and received no monetary compensation for their contributions to the project. Two EAB members still serve in an advisory capacity when needed.

During this phase, the EAB reviewed findings from the environmental scan and provided input into the development of the algorithm for assessing a patient's risk for developing

neutropenia. During later phases of the project, EAB members reviewed focus group findings, evidence-based content for the website, branding concepts, a pilot testing plan, and dissemination strategies. Members of the EAB also assisted in other specific tasks. For example, the CDC conducted a site visit to one of the member's outpatient clinics to better understand potential obstacles and facilitators in incorporating a web-based educational tool into a practice. In addition, several EAB members contacted representatives from their respective professional organizations to increase awareness, dissemination, and use of the website.

Phase 3: Concept Validation

A webinar was conducted with five researchers and health-care providers (including urban and rural oncology nurses, an oncologist, and an infectious disease physician) to further inform development of the website. Webinar participants were selected based on their experience working with patients with cancer or their expertise in infection control. The main objectives of the webinar were to confirm the findings of the environmental scan (i.e., the risk factors for developing neutropenia among patients with cancer), reach a consensus on questions for the website's algorithm, review the website's draft content, and obtain input on the delivery, use, and limitations of the website.

After the webinar was completed, 11 focus groups were conducted with a total of 64 cancer survivors, caregivers, and healthcare providers to better understand the perspectives of these audiences on preventing infections during cancer treatment and an online patient education tool (see Table 1). The focus groups were an important component of the concept validation phase in that they allowed direct interaction and conversation with the audiences for whom the website is intended.

Recruitment for all groups was conducted through local cancer centers, support groups, professional medical associations, and patient advocacy organizations. Content from the focus groups was transcribed and reviewed to conduct a content analysis of themes across all 11 focus groups that informed development of the website. As an example, to increase user acceptance, three preliminary website designs were evaluated by the patient, caregiver, and healthcare provider focus groups. Participants were asked to provide feedback on colors, images, graphic elements, structure, and content. One design was selected most frequently across all focus group participants and was ultimately chosen, with participants' suggested revisions incorporated.

Phase 4: Website Development, Testing, and Launch

A web developer and database programmer used HTML and Microsoft.NET™ technologies to create the site. Many of the development tasks centered on integrating website design specifications, algorithm logic, and tailored infection control and prevention messages. The environmental scan revealed that the Internet has become a leading source for health information. However, to reach targeted audiences and ensure adoption of recommended practices and behaviors, information must be appealing, easy to understand, and educational (Bensley et al., 2004). During the development phase, the team was mindful of maintaining readability of the materials using plain language tactics to ensure a user-friendly website,

such as incorporating bullet lists and short paragraphs and sentences (Plain Language.gov, 2011). The project team aimed to keep the website content to a sixth grade reading level; however, the necessary use of medical terminology increased the content to a seventh grade level. As a result, a glossary was added to provide users with definitions of this terminology in lay terms.

A development approach was employed that enables future modifications with minimal effort, therefore providing maximum flexibility for updates. The development approach also included the use of the software development life cycle method to guide the process and ensure the website met industry standards (Conger, 1993). Once a preliminary version of the website was complete, pilot testing was conducted with 24 respondents (physicians, nurses, caregivers, and patients) who had previously participated in the focus groups. Data were collected through a short, web-based survey. Information gathered from pilot testing, including quantitative satisfaction results and qualitative comments, were summarized and minor edits were made to clarify glossary terminology and risk assessment completion instructions.

Following these website revisions, promotional activities began by targeting key partner groups such as patient advocacy organizations, federal agencies, state and national organizations, as well as oncology, nursing, and infectious disease associations and societies. To garner support for the website and inspire key groups to promote and embed the website into their organizations' existing websites, social media channels, and email blasts/communications to their memberships, the CDC conducted three teleconferences with these various partner organizations the week before the website was launched. The partners received a variety of resources, including the embargoed press release, fact sheets, posters, key messages, web buttons, tweets, e-cards, and an educational video explaining how to use the website and its benefits. Many partners posted this information on their organizations' websites, sent out a separate email to their membership, and/or posted one of the web badges (directly linking the user to www.preventcancerinfections.org) on their own organization's site. Partner efforts helped to drive traffic to the website and added to its exposure.

Using multiple marketing and dissemination channels to reach a diverse target audience was critical to the launch of the website on October 25, 2011. In addition to partners, the development group targeted traditional print and Internet-based media to ensure appropriate saturation for maximum audience exposure. Online and print coverage alone reached more than 12 million readers and helped drive the public to the site. In addition, a satellite media tour was conducted that had the potential to reach 2.9 million people. The developers also used social media outlets, including Facebook and Twitter, which garnered 357 total tweets, reaching more than 885,000 people. By using this multifaceted approach, the launch of resources alone reached more than 168 million impressions and more than 273 million impressions as of May 2013.

Phase 5: Maintenance and Initial Evaluation Activities

A maintenance phase has been in place since the launch. The goal is to track and document user feedback, monitor risk assessment questionnaire data, and track site usage through web analytics. Although users do not receive responses to their comments, the feedback feature

provides a mechanism for capturing accessibility, content, and/or general user concerns. In addition, data gathered from completed risk assessment questionnaires provide a snapshot of the demographic and clinical characteristics of website users. Web analytics data (e.g., site usage, sources of site traffic, average time on site, most frequently accessed content) also are analyzed and reported weekly (see Table 2).

Initial evaluation activities also were conducted during this phase to expand the understanding of how the website is used and incorporated into outpatient clinical settings. Site visits to two outpatient cancer treatment facilities were conducted and included in-depth interviews with staff and patients. Both facilities were identified and selected based on their staff's involvement in the EAB and their use of the website within their facilities. Findings from these visits provided a concrete understanding of how the website and its collateral materials are used in the outpatient clinical setting (see Figure 2). Summary reports were developed, providing key information regarding the availability of process (e.g., the various ways the website is used by providers and patients) and outcome data (e.g., infection rates) that may help to inform the design of a more rigorous evaluation of the website.

As a final evaluation activity, interviews were conducted to gather input and lessons learned from two websites with similar content, purpose, and audiences. Telephone interviews with individuals who were responsible for the development, marketing, and maintenance of these websites were conducted strictly for information-gathering purposes. All qualitative and statistical data captured during this phase will inform future website enhancements, as well as marketing, website optimization, and evaluation activities.

Discussion

The published literature reviewed in the environmental scan indicated that a large body of health information is available to patients with cancer on the Internet. Few sites, however, offer specific information on infection control among patients with cancer. In addition, the gray or unpublished literature reviewed in the environmental scan revealed an abundance of cancer-related patient education information on the Internet, but few online patient education programs were designed specifically for infection control among patients with cancer.

As patients and caregivers frequently look to the Internet to obtain relevant health information, an online program may be an effective way to provide patients with information to prevent infections. PreventCancerInfections.org can be a valuable addition to oncology nurses' "toolbox" of tools and resources that help educate and empower patients.

In addition to being one of few resources of its kind, another unique benefit of this website is that it reflects the insights and recommendations of prominent researchers and healthcare providers, the EAB, and intended users (including patients and caregivers). The project team used the best available information to create the website and educational messages. Since the website's intended users represented a mixed audience (e.g., patients with cancer, caregivers, healthcare providers), the project team was able to ensure the program would benefit all audiences by seeking their input at multiple phases of development. In addition,

the healthcare providers who participated in the focus groups and the EAB represent professional diversity with areas of expertise that were pivotal in evaluating the website for essential content, content validity, and usability benefits and challenges.

In addition, many EAB members have indicated a willingness to assist the CDC's efforts with ongoing website refinement, promotion, and evaluation. The ultimate goal is to develop methods for sustainability of a user-friendly, credible, trusted, and interactive web-based resource designed for patients with cancer undergoing chemotherapy.

One limitation identified in the initial evaluation site visits is that increased use of the website may not be feasible for many outpatient facilities given technological challenges (computer and Internet access), patient volume, and staff demands. However, increased use of the website's collateral materials is certainly something that can be accomplished. These materials exist in the form of fact sheets, brochures, magnets, and other promotional items. One way to ensure and increase the use of the PreventCancer Infections.org materials is to encourage outpatient facilities to make these resources a consistent, permanent, and mandatory part of their patient education and services.

Finally, the developers recognized the importance of ongoing, targeted marketing efforts to promote use of the website as well as evaluation activities to better understand patterns of use. To help champion the CDC's targeted marketing efforts, the U.S. Oncology Network, one of the nation's largest networks of community-based oncology physicians, reached out to its membership through an email blast, introducing its members to the website and its collateral materials. The developers are continuing to identify other similar opportunities for partnership in promotion of the website. Also, methods to determine if exposure to this information leads to improved outcomes for patients with cancer, including a decrease in infections, and an increase in recognizing signs and symptoms by patients and caregivers which would lead to earlier diagnosis and treatment, are being explored. If evaluation findings warrant, future activities may also include tailoring and refocusing the delivery of website materials to adolescent, low literacy, and minority populations.

Conclusion

About 650,000 patients with cancer receive chemotherapy in an outpatient setting annually in the United States (Halpern & Yabroff, 2008). Neutropenia is a common and potentially dangerous side effect of chemotherapy and results in preventable morbidity and mortality. Many patients with cancer and their caregivers may not be aware of this risk and actions they can take to minimize their risk of infection. PreventCancer Infections.org is an interactive, evidence-based tool for providing information and education to patients with cancer undergoing chemotherapy. The goal of the website is to empower patients and their caregivers with the knowledge and skills to recognize the signs and symptoms of infection. This information should lead patients and caregivers to take actions to seek care for this life-threatening condition.

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Implications for Practice

- Educate patients about neutropenia, a common and potentially dangerous side effect of chemotherapy that may lead to significant morbidity and mortality.

- Inform patients with cancer and their caregivers about the risk of infection in community and healthcare settings and provide them with steps they can take to minimize risk.

- Develop an online program as an effective way to provide information on the prevention of infections to patients with cancer and their caregivers.

1. Have you ever had or are you scheduled to get a stem cell transplantation or a bone marrow transplantation?

   Yes   No   I don't know.

2. Are you receiving or scheduled to receive chemotherapy?

   Yes   No   I don't know.

3. Age (years)?

   0–17   18–64   65 or older

4. Gender?

   Male   Female

5. Do you have any of the following conditions? (Check all that apply.)

   ❏ Autoimmune disease
   ❏ Diabetes
   ❏ Kidney disease
   ❏ Liver disease
   ❏ None
   ❏ I don't know.

6. What type of cancer do you have?

❏ ALL	❏ Fallopian tube	❏ Pancreatic	❏ Pediatric–Wilms tumor
❏ AML	❏ Gall bladder	❏ Pediatric–ALL	❏ Penile
❏ Anal	❏ Head and neck	❏ Pediatric–AML	❏ Prostate
❏ Appendiceal	❏ Esophageal	❏ Pediatric–Brain tumor	❏ Rectal
❏ Bladder	❏ Hodgkin lymphoma	❏ Pediatric–Carcinomas	❏ Sarcoma
❏ Brain	❏ Kidney	❏ Pediatric–CLL	❏ Skin (melanoma)
❏ Breast	❏ Liver	❏ Pediatric–Hepatoblastoma	❏ Stomach (gastric)
❏ Cervical	❏ Lung	❏ Pediatric–Hodgkin lymphoma	❏ Testicular
❏ CLL	❏ Mesothelioma	❏ Pediatric–Neuroblastoma	❏ Thyroid/thymus
❏ CML	❏ Multiple myeloma	❏ Pediatric–NHL	❏ Uterine
❏ Colon	❏ NHL	❏ Pediatric–Retinoblastoma	❏ Vaginal/vulvar
❏ Endometrial	❏ Ovarian	❏ Pediatric–Sarcomas	❏ Other

7. What is your stage of cancer? (Choose one.)

   I   II   III   IV   I don't know.

8. Have you received chemotherapy, radiation, and/or biotherapy treatments in the past?

   Yes   No   I don't know.

   If *yes*, were you ever told that you had a low white blood cell count?

   Yes   No   I don't know.

9. Which choice best describes you? (Choose one.)

   ❏ I am fully active and able to do all of the activities that I could before I became sick.
   ❏ I cannot do heavy activities, but I can do light activities and things that don't require me to stand for long periods of time (e.g., light house work, office work).
   ❏ I can take care of myself, but I cannot go to work. I am up and out of bed more than half of the time I am awake.
   ❏ I can take care of myself with some help. I spend most of the time that I am awake in a bed or chair.
   ❏ I am not able to take care of myself in any way. I spend all of my time in a bed or chair.
   ❏ I don't know.

ALL—acute lymphoblastic leukemia; AML—acute myelogenous leukemia; CLL—chronic lymphocytic leukemia; CML—chronic myelogenous leukemia; NHL—non-Hodgkin lymphoma

FIGURE 1.
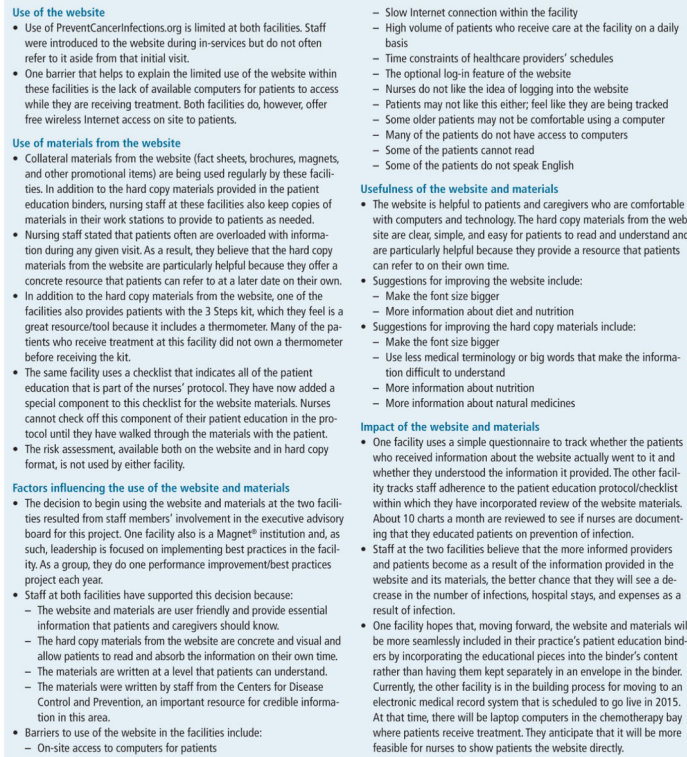Questions Included in the Patient Risk Assessment

Use of the website
- Use of PreventCancerInfections.org is limited at both facilities. Staff were introduced to the website during in-services but do not often refer to it aside from that initial visit.
- One barrier that helps to explain the limited use of the website within these facilities is the lack of available computers for patients to access while they are receiving treatment. Both facilities do, however, offer free wireless Internet access on site to patients.

Use of materials from the website
- Collateral materials from the website (fact sheets, brochures, magnets, and other promotional items) are being used regularly by these facilities. In addition to the hard copy materials provided in the patient education binders, nursing staff at these facilities also keep copies of materials in their work stations to provide to patients as needed.
- Nursing staff stated that patients often are overloaded with information during any given visit. As a result, they believe that the hard copy materials from the website are particularly helpful because they offer a concrete resource that patients can refer to at a later date on their own.
- In addition to the hard copy materials from the website, one of the facilities also provides patients with the 3 Steps kit, which they feel is a great resource/tool because it includes a thermometer. Many of the patients who receive treatment at this facility did not own a thermometer before receiving the kit.
- The same facility uses a checklist that indicates all of the patient education that is part of the nurses' protocol. They have now added a special component to this checklist for the website materials. Nurses cannot check off this component of their patient education in the protocol until they have walked through the materials with the patient.
- The risk assessment, available both on the website and in hard copy format, is not used by either facility.

Factors influencing the use of the website and materials
- The decision to begin using the website and materials at the two facilities resulted from staff members' involvement in the executive advisory board for this project. One facility also is a Magnet® institution and, as such, leadership is focused on implementing best practices in the facility. As a group, they do one performance improvement/best practices project each year.
- Staff at both facilities have supported this decision because:
  - The website and materials are user friendly and provide essential information that patients and caregivers should know.
  - The hard copy materials from the website are concrete and visual and allow patients to read and absorb the information on their own time.
  - The materials are written at a level that patients can understand.
  - The materials were written by staff from the Centers for Disease Control and Prevention, an important resource for credible information in this area.
- Barriers to use of the website in the facilities include:
  - On-site access to computers for patients

  - Slow Internet connection within the facility
  - High volume of patients who receive care at the facility on a daily basis
  - Time constraints of healthcare providers' schedules
  - The optional log-in feature of the website
  - Nurses do not like the idea of logging into the website
  - Patients may not like this either; feel like they are being tracked
  - Some older patients may not be comfortable using a computer
  - Many of the patients do not have access to computers
  - Some of the patients cannot read
  - Some of the patients do not speak English

Usefulness of the website and materials
- The website is helpful to patients and caregivers who are comfortable with computers and technology. The hard copy materials from the website are clear, simple, and easy for patients to read and understand and are particularly helpful because they provide a resource that patients can refer to on their own time.
- Suggestions for improving the website include:
  - Make the font size bigger
  - More information about diet and nutrition
- Suggestions for improving the hard copy materials include:
  - Make the font size bigger
  - Use less medical terminology or big words that make the information difficult to understand
  - More information about nutrition
  - More information about natural medicines

Impact of the website and materials
- One facility uses a simple questionnaire to track whether the patients who received information about the website actually went to it and whether they understood the information it provided. The other facility tracks staff adherence to the patient education protocol/checklist within which they have incorporated review of the website materials. About 10 charts a month are reviewed to see if nurses are documenting that they educated patients on prevention of infection.
- Staff at the two facilities believe that the more informed providers and patients become as a result of the information provided in the website and its materials, the better chance that they will see a decrease in the number of infections, hospital stays, and expenses as a result of infection.
- One facility hopes that, moving forward, the website and materials will be more seamlessly included in their practice's patient education binders by incorporating the educational pieces into the binder's content rather than having them kept separately in an envelope in the binder. Currently, the other facility is in the building process for moving to an electronic medical record system that is scheduled to go live in 2015. At that time, there will be laptop computers in the chemotherapy bay where patients receive treatment. They anticipate that it will be more feasible for nurses to show patients the website directly.

FIGURE 2.
Findings From the Two Evaluation Site Visits

TABLE 1

Focus Group Audiences and Modes

Audience	Number of Focus Groups	Focus Group Mode
Patients with cancer (age 30 and older)	3	Telephone
Caregivers of patients who are ages 0–17	2	In-person (Atlanta)
Caregivers of patients who are ages 18 and older	2	In-person (Atlanta)
Physicians	2	Online/webinar format
Nurses, including office managers	2	Online/webinar format

TABLE 2

Selected Elements of Web Metrics*a*

Metric	Data
Number of visits to the site	36,757
Page views	150,241
Pages per visit	2.52
Average visit duration (minutes)	2:00

*a*As of July 1, 2014