

# Evaluation of NCI-Designated Cancer Center and Comprehensive Cancer Center Survivorship-Focused Websites: Information Provided and Accessibility

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## Abstract

**Background:** Individuals with a history of cancer increasingly seek health information from online resources, including NCI-designated Cancer Center websites. Centers receive NCI designation because they provide excellent care and engage in cutting-edge research. However, the information presented on these webpages and their accessibility is unknown. An evaluation of the survivorship-focused webpages from NCI-designated Cancer Centers is needed to assess survivorship information and accessibility of these webpages. **Methods:** We conducted an evaluation of the survivorship-focused webpages from 64 NCI-designated Cancer Centers. We evaluated where survivorship-focused webpages were housed, if there was a survivorship clinic or program, target audience of the webpage, how cancer survivor was defined, contact methods, and available resources. Accessibility outcomes included readability, font type, font size, color scheme, and alternative text (alt text) descriptors. An artificial intelligence (AI) audit was conducted to assess if the webpage was compliant with national accessibility guidelines. **Results:** Most cancer centers had a survivorship-focused webpage, with 72% located on the cancer center's website and 28% on a health system website. Survivorship information available varied considerably and was often lacking in detail. Although three-quarters of webpages targeted patients only, variable definitions of cancer survivor were observed. Accessibility issues identified included inconsistent use of alt text descriptors, font size smaller than 15 points, and color schemes without adequate contrast. The average reading-level of information presented was above 12th grade. Only 9% of webpages were compliant with online accessibility guidelines; 72% semicompliant and 21% were noncompliant. **Conclusions:** Information presented on NCI-designated Cancer Center survivorship-focused webpages was inconsistent, often lacking, and inaccessible. NCI-designated Cancer Centers are role models for cancer research in the United States and have an obligation to provide survivorship information. Changes to content and website design are needed to provide better information for individuals seeking resources and health information relative to their cancer and care.

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## Background

Online health information seeking has become increasingly prevalent,<sup>1</sup> and is common among individuals with a history of cancer.<sup>2–5</sup> Due to late and long-term effects of cancer and treatments, individuals with a history of cancer may have unique information needs.<sup>4,6</sup> Although cancer survivors often report their physician is their preferred information source, many seek information online.<sup>3,4,7</sup> The growing use of the internet for health information may be related to increasing patient engagement,<sup>3</sup> but may stem from the failing structural capacity of the health care system to provide care for survivors.<sup>8</sup> Many cancer survivors have unmet information needs<sup>4</sup> and report negative information-seeking experiences.<sup>2</sup> Due to the high volume of information available, finding appropriate online sources can be time-intensive and challenging.<sup>4,6,8</sup>

Given these challenges, cancer survivors report relying on nonprofit, government, and cancer center online sources they perceive as trustworthy.<sup>8</sup> In the United States, there are currently 65 NCI-designated Cancer Centers and Comprehensive Cancer Centers, and the number of patients seeking care at these sites is rapidly growing.<sup>9</sup> These centers receive NCI designation because they provide excellent care and engage in cutting-edge scientific discovery.<sup>6,10</sup> Most individuals in the United States receive care at community cancer centers that look to NCI sites to provide resources and guidance.<sup>6</sup> A 2018 study evaluating available survivorship

resources on the websites of the then 47 Comprehensive Cancer Centers found only 75% had discoverable survivorship information. Furthermore, information found was minimal.<sup>6</sup> In the 5 years since that study, funding for survivorship care has increased significantly, but it is unknown if this has impacted resources on and quality of these websites.<sup>11</sup>

Online information for patients is often a crucial part of their illness experience, having been found to support treatment and health behavior decisions, feelings of preparedness during clinic encounters, and navigating new health statuses and identities as well as the socioemotional consequences of disease.<sup>8,12</sup> To best achieve these ends, accessible information must be presented. An accessible online resource is one that can be assessed by all individuals regardless of disability. Issues with accessibility of online resources can occur for individuals with visual impairments, including blindness or colorblindness; motor impairments impacting the ability to click buttons or move a mouse; learning disabilities such as processing disorders or dyslexia; and other conditions that impact how information is processed.<sup>13</sup> Additionally vital is readability, given that the average American has a reading level between 7th and 8th grade.<sup>14</sup> Accessible webpages increase the likelihood that individuals can access the information they need.

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Although the Americans with Disabilities Act (ADA) and the Plain Writing Act of 2010 include recommendations that would increase website accessibility,<sup>14,15</sup> neither provides technical standards, and enforcement and compliance are questionable. Prior research in various clinical areas has highlighted issues with readability and quality of online resources,<sup>14,16-20</sup> and a recent report identified significant accessibility issues on national hospital and cancer hospital websites.<sup>20</sup> In this study, we sought to evaluate survivorship information provided on websites of NCI-designated Cancer Centers and Comprehensive Cancer Centers to identify where information is located, who the audience is, and what content is provided, and evaluate the accessibility of the content. Based on our findings, we created a checklist of important components to consider in the creation of informative and accessible webpages for future use.

## Methods

For this website evaluation, a list of NCI-designated Cancer Centers and Comprehensive Cancer Centers was generated from the NCI directory.<sup>10</sup> At the time, there were 64 sites: 56 Comprehensive Cancer Centers and 8 Cancer Centers. Searches were conducted via Google using predefined keywords and search strings including “[cancer center name]” + “survivorship” or “survivor.” However, the study team was aware of programs that were not identified using these search terms and decided this was not an effective search strategy. The team revised the search strategy and conducted additional searches using website internal search engines, searching by section through websites (ie, supportive care services) and searching websites of larger hospital systems. “Survivor” and “survivorship” were used interchangeably, and no programs were excluded based on how they defined these terms. Searches were conducted between May and August 2022 by a research team member. The study team reviewed a sample of webpages and met to discuss questions as they arose. In this study, a “webpage” is defined as a single page on a website (ie, a survivorship webpage), and a “website” is a collection of webpages linked to a single domain (ie, the cancer center website).<sup>21</sup>

## Survivorship Information

The team extracted information from survivorship webpages, including where the webpage was housed (on the cancer center website or health system website) and whether there was a survivorship clinic or program as part of the cancer center or in partnership with the cancer center (ie, a survivorship program affiliated with the larger hospital system; see Appendix 1 in the supplementary materials, available online with this article). A health system website was defined as the website of the larger system that comprised the cancer center or an affiliate (ie, medical school). We also captured if there was a specific clinic for childhood or adolescent cancer survivors.

The target audience of the survivorship webpage was categorized as either patient-focused, clinician-focused, researcher-focused, a combination, or unclear. For example, a webpage that began, “Now you have completed your cancer treatment...” was coded as patient-focused, whereas one explicitly noting that the program seeks to educate clinicians about survivorship was coded as clinician-focused. Webpages coded as unclear typically provided minimal information, such as only describing survivorship statistics.

Contact information and method, such as telephone number, email address, or ability to make an appointment online, were also recorded. Resources available for childhood cancer or young adult cancer survivors were additionally noted. We also documented if additional survivorship resources, such as information about lymphedema, counseling, physical therapy, support groups, and nutrition, were available and linked. Finally, it was noted if webpages discussed or mentioned survivorship care plans.

## Accessibility

Information about accessibility of webpages was also abstracted. This included 3 readability measures: words per sentence, Flesch-Kincaid Grade (FKG), and Flesch Reading Ease score (FRE). Words per sentence is an important readability metric because longer sentences are more difficult to understand.<sup>22</sup> FKG and FRE are calculated through simple formulas factoring in word and sentence length. FKG provides a numerical score corresponding to the education level required to read text comfortably (ie, 7 is 7th grade reading level). FRE results in a score between 0 and 100, with a lower score indicating information that is more challenging to read (ie, 70–80 is 7th grade reading level).<sup>16</sup> Although there are many other statistics of readability, calculations can be complicated.<sup>16</sup> FRE and FKG can be easily checked using Microsoft Word and other free online tools, which may make them more accessible.

Accessibility additionally includes visual components, such as color contrast and saturation, which impact individuals with color vision or other vision issues. Font type (serif vs sans serif fonts), font size, use of text headers, and alternative text (alt text) descriptors for visual elements are additionally important.<sup>23</sup> More information about these design elements is included in Table 1. Descriptive information about these accessibility components, such as font type and use of headers, were captured through visual assessment and confirmed by reviewing webpage code. An artificial intelligence (AI) audit assessing compliance with ADA and Web Content Accessibility Guidelines (WCAG) 2.1 was completed using the online tool accessScan.<sup>24</sup> accessScan is a free online website evaluation tool previously used in similar studies to evaluate health system websites.<sup>20</sup> This tool assesses if a webpage is “compliant,” “semi-compliant,” or “non-compliant.” A “compliant” website adheres to web accessibility guidelines, whereas a “semi-compliant” website is missing fundamental WCAG elements. A “non-compliant” website does not comply with WCAG or other accessibility guidelines.<sup>24</sup>

## Results

Webpages with survivorship information were identified on 95% (61/64) of websites: 7 of 8 Cancer Centers websites and 54 of 56 Comprehensive Cancer Center websites. One webpage was removed during this project, and another noted the adult survivorship clinic was “no longer active,” though there was a clinic for children and adolescents. Nearly three-quarters of survivorship webpages were located on a cancer center website ( $n=44$ ; 72.1%), but more than a quarter ( $n=16$ ; 26.2%) were on another website within the health system (ie, medical school, hospital, or larger health system) that was not linked to the cancer center’s website (Table 2).

Three levels of survivorship resources were identified: (1) information only, (2) has a survivorship program, (3) and has a

**Table 1.** Design Elements, Considerations, and Guidance for Website Design

Design Element	Considerations	Guidance
Color choices	Avoid using colors that cannot be seen by individuals with vision issues such as colorblindness. <sup>40</sup> Do not use color as the only marker of importance in text. <sup>41</sup>	No color choices are specifically prohibited, but contrast ratios between text and background must be considered.
Color contrast	Avoid color combinations with low contrast ratios to ensure readability by individuals with visual difficulties. <sup>40</sup>	Headings: Contrast ratio should be a minimum of 3:1. Main text: For text other than headings, ensure the contrast ratio is at least 4.5:1. <sup>42</sup>
Bolded/Italicized text	Bold and italics often denote emphasis, but can reduce the readability of text for many individuals, including those with dyslexia. <sup>43</sup> Bold and italicized text are often not read by screen readers, eliminating the emphasis for those who cannot see the text. <sup>44,45</sup>	Avoid using italic text in large chunks. <sup>46</sup> Bolded text should have appropriate tags in code to allow nonvisual readers access to information. Preferred methodology is use of semantic tags <code>&lt;strong&gt;</code> and <code>&lt;em&gt;</code> rather than bold and italics. <sup>45</sup>
Alternative text (alt text) descriptors	Images on webpages can display content or serve a function but cannot be seen by all individuals and must have alt text descriptions to be read by screen readers. <sup>47</sup>	Use alt text descriptors for all visual elements, including images and buttons, and ensure appropriate coding is used in text. <sup>48</sup>
Text headers	Text headers of varying weight help break up text into sections. This helps individuals with screen readers know when they have moved onto a new section of text. Furthermore, this helps individuals with learning disabilities organize information, and helps individuals navigate webpages. <sup>49</sup>	Whenever possible, headers should be used to denote different sections of text and included in code. <sup>50</sup> A combination of size, weight, face, and color can ensure headers are visually distinct from the main text. <sup>51</sup>
Text sizing and spacing	Text should be large enough to be comfortably read by all individuals. <sup>51</sup> Spacing between lines should be considered, because spacing that is too tight or loose reduces readability. <sup>51</sup>	Font of main text should be at least 16 points. <sup>51</sup> Furthermore, text should be able to be resized to at least 200% its original size. <sup>48</sup> Line spacing should be at least 1.5 lines within paragraphs, and at least 1.5× lines between paragraphs. <sup>42</sup>
Text font	Accessible fonts are legible and have a good height, width, and thickness. Fonts with decorative elements like serif fonts can be less readable for many individuals. <sup>52</sup>	Main text should be set in a sans serif font, which is more readable for many individuals. <sup>43</sup>

survivorship clinic. Survivorship programs generally provide more comprehensive survivorship care than survivorship clinics. Nearly 70% of cancer centers (n=42) noted having a survivorship program, but fewer (n=35; 57.4%) had a survivorship clinic. It was often unclear whether these clinics served patients with multiple cancer types, and most appeared to be disease-specific, limited to breast, head and neck, or colorectal cancer survivors. On nearly one-fifth of webpages (n=12; 19.7%), it

was unclear whether a survivorship clinic existed given limited information.

A definition of cancer survivor was found on 42 webpages (68.9%) but varied considerably. Some centers adopted the NCI-definition that survivorship begins at diagnosis, whereas others defined cancer survivorship as beginning “posttreatment.” For others, survivorship was defined in reference to time since end of treatment or diagnosis, such as having been cancer-free for at

**Table 2.** Survivorship Webpage Information and Features Results

	Present on Website n (%)	Not Present on Website n (%)	Unclear n (%)
<b>Information Location and Features</b>			
On cancer center website <sup>a</sup>	44 (72.1%)	17 (27.9%)	
On health system website <sup>a</sup>	16 (26.2%)	45 (73.8%)	
Survivorship program	42 (68.9%)	15 (24.6%)	4 (6.6%)
Survivorship clinic	35 (57.4%)	14 (23.0%)	12 (19.7%)
Definition of cancer survivor	42 (68.9%)	19 (31.1%)	
Phone number	44 (72.1%)	17 (27.9%)	
Email	13 (21.3%)	48 (78.7%)	
Request online	10 (16.4%)	51 (83.6%)	
Information for young adults/childhood cancer survivors	35 (57.4%)	26 (42.6%)	
Resources noted	49 (80.3%)	12 (19.7%)	
Resources linked	42 (68.9%)	19 (31.1%)	
Mention SCP	34 (55.7%)	27 (44.3%)	
<b>Website Target</b>			
Patients only	46 (75.4%)		
Patients + clinicians	3 (4.9%)		
Patients + researchers	4 (6.7%)		
Other combination	4 (6.7%)		
Unclear	4 (6.7%)		

Abbreviation: SCP, survivorship care plan.

<sup>a</sup>Not including one center on neither a health system nor a cancer center website but rather on a health system–affiliated website.

least 2 years posttreatment. Phone numbers were the most common type of contact information available (n=44; 72.1%), with email addresses (n=13; 21.3%) and links to requesting appointments online (n=10; 16.4%) less common. Patients were often instructed to talk to their oncologist or care team for a referral to the survivorship clinic/program.

Aside from a few nationally recognized programs, survivorship webpages provided few details about survivorship-specific resources. Links to informational resources were present on 42 (68.9%) websites but were often nonspecific to cancer survivors. For instance, lymphedema resources were often written for individuals actively receiving breast cancer treatment.

Patients were the target audience of 75.4% (n=46) of webpages, but webpages targeting patients and clinicians (n=3) or patients and researchers (n=4) were also noted. Four webpages targeted other groupings, including researchers and clinicians and researchers only. On 4 (7%) webpages the target audience was unclear, typically because text was limited.

### Accessibility

Webpages were evaluated using accessScan to assess compliance with ADA and WCAG 2.1 guidelines (Table 3). Only 7.8% (n=5) of webpages were compliant. A total of 41 (64.1%) webpages were semicompliant, and 12 (18.8%) were noncompliant; 3 webpages were not evaluable because of blocks in their code preventing an audit or other website issues. The average sentence was 19 words long, and the average reading level of text was above 12th grade. Although the average font was 16 points, small fonts were commonly used for captions and contact information. Most (n=53; 86.9%) websites used a sans serif font. A simple color scheme of dark text and a white background was most prevalent, but different color text and background combinations were noted, including gray text on a light gray background, blue text on a black background, and other low-color contrast combinations. Twenty percent of sites had no images (n=13), but alt text descriptors of what an image is and how it relates to website content were present on the majority of webpages with images (n=31/48), although not uniformly even on the same webpages.

### Discussion

Cancer survivorship is part of the cancer care continuum, but survivorship information provided by NCI-designated Cancer Centers and Comprehensive Cancer Centers was inconsistent

and often lacking and/or inaccessible. These NCI-designated centers are role models for community cancer centers and should be leaders in making information accessible and available.<sup>6</sup> Their websites should be trustworthy information sources for individuals from cancer centers and community centers alike. Failing to provide survivorship information, or providing confusing and inconsistent information, may increase stress and decrease individuals' ability to identify reliable sources.<sup>25,26</sup>

This study did not aim to mimic how individuals search for information, which is often through search terms related to their disease,<sup>8</sup> but rather to identify survivorship information available on these websites. Finding this information was surprisingly challenging, even using broad search terms such as "survivor" or "survivorship." For nearly 30% of sites, the survivorship-focused webpage was not located on the cancer center website but rather the website of the larger parent health system. These larger systems do not always share a name with the cancer center, and unless an individual has prior knowledge, they may not understand how these organizations are related.

A useful webpage should be both informative and accessible, and survivorship webpages identified in this study often failed to achieve both goals. Improving these webpages should be a priority for cancer centers to educate patients and provide cancer-related information. Additionally, there is a very real risk of litigation for failing to adhere to ADA website accessibility standards.

Webpages identified in this study often provided vague or sparse survivorship-focused information. This echoed the 2018 finding of Rolland and Eschler,<sup>6</sup> who found that most NCI-designated Comprehensive Cancer Centers' survivorship webpages did not provide enough information about survivor-specific services. This study further expands on their findings, including an additional 8 NCI-designated Comprehensive Cancer Centers and 8 NCI-designated Cancer Centers. Missing was basic standardization of information, such as links to national resources. Many national and governmental organizations, including the NCI,<sup>27</sup> the CDC,<sup>28</sup> and the American Cancer Society,<sup>29</sup> have survivorship-focused webpages. Including links to these webpages would be an easy way to provide basic resources and information, especially for centers without a survivorship clinic or program.

Furthermore, missing across these webpages was a standard definition of cancer survivor. Although some institutions follow the NCI definition of a cancer survivor as anyone from the time of diagnosis,<sup>30</sup> others noted cancer survivorship begins when treatment is completed or even years later. These varying definitions likely create uncertainty for patients, who may struggle to understand whether information presented is relevant to them or if they are eligible for services. Furthermore, the specificity of some definitions may be confusing for patients whose treatment did not fall within the parameters defined, such as those whose treatment was surgery alone, radiation alone, or other. Many webpages referred to survivors as being posttreatment, but there are many individuals with chronic cancers who are never posttreatment, or those who are in a watchful-waiting stage. Additionally, not all patients are "cured," and many live with metastatic cancers for years but may find survivorship resources helpful. These different definitions of survivorship likely serve to restrict access to limited services, but presenting conflicting information may cause confusion for patients.

Accessibility of information presented on these webpages was also concerning. Fewer than 10% of survivorship webpages

**Table 3.** Survivorship Webpage Accessibility Results

	n (%)
accessScan results	
Non-compliant	12 (18.8%)
Semi-compliant	41 (64.1%)
Compliant	5 (7.8%)
Not evaluable	3 (4.7%)
No survivorship center	3 (4.7%)
Accessibility metrics	
Words per sentence, median	19.0
FK reading level, median	12.5
FK reading ease score, median	38.8
Sans serif fonts	53 (86.9%)

Abbreviation: FK, Flesch-Kincaid.

were ADA- and WCAG 2.1-compliant, which is consistent with recent findings from an audit of online home pages of top hospitals. Of the 46 cancer hospitals included in that study, only 4.4% were compliant.<sup>20</sup> A webpage that is compliant is not necessarily good or informative, rather this designation tells whether a webpage meets basic accessibility guidelines. Most webpages in our study were semicompliant, meaning they met some but not all guidelines, and 19% were noncompliant, indicating serious issues and failure to comply. Web accessibility is the law, and cancer centers must begin to take accessibility guidelines seriously.

Not included in accessScan's AI audit are metrics related to readability—the ability to read and comprehend written information, which is an important factor in literacy.<sup>31</sup> In the United States, 50% of individuals have below-proficient literacy, with nearly 20% categorized as having low literacy, and therefore may struggle drawing inferences or evaluating information.<sup>31–33</sup> As publicly available resources, the reading level of these webpages should be 6th grade, but was on average 12th grade.

Literacy is an important component of health literacy—the ability to identify, understand, and use health information presented.<sup>34,35</sup> In a study analyzing data from the 2016 Behavioral Risk Factor Surveillance System (BRFSS), 1 in 6 cancer survivors reported having low health literacy, and low literacy was more prevalent among Black and Hispanic cancer survivors and those with lower education levels.<sup>36</sup> Health literacy is positively associated with the ability to both evaluate online resources and trust internet health resources. Low health literacy negatively impacts ability to evaluate trustworthiness and information found on webpages<sup>37</sup> and may lead to information overload.<sup>38</sup> Information overload—when information presented exceeds an individual's processing capability—is associated with stress, anxiety, and anger.<sup>38</sup> Low health literacy has also been linked to outcomes such as poor physical functioning and lower utilization of health services.<sup>36</sup> Although figures or diagrams may increase comprehension, web developers need to be aware of common pitfalls, including small font, missing alt text, and nonscalable images.

Taking time to create websites that meet accessibility standards and provide useful information is an investment in the future of cancer survivorship. Individuals with a history of cancer will continue seeking information online and should be able to find informative, accessible resources. Improving webpage accessibility may also positively impact patient experience incorporating features to help create more aesthetically comfortable websites.<sup>8</sup> Time and resources should be invested in making the information presented on these websites useful to patients and families seeking this information. With this in mind, we created a checklist of questions to consider when creating a survivorship-focused website (Table 4). This checklist is not comprehensive, but we hope it will provide some guidance about important elements that must be considered in information exchange. Additionally, website developers should use free tools such as accessScan or WAVE, a suite of web accessibility evaluation tools, that highlight issues such as contrast ratio errors, missing alt text descriptors, and broken navigation links.<sup>39</sup> Simple changes to these websites to meet ADA and WCAG guidelines, as well as changes to reduce the reading level, will both increase the accessibility of the information and reduce the risk of litigation for cancer centers.

This study has several important limitations. We attempted to identify the main survivorship webpage of centers, but information may be duplicated in other places on websites. Additionally, although many webpages did not appear to be updated regularly, this was often unclear, and there may have been updates since our review was completed. Finally, although we used multiple readability measures, other measures might have provided additional information about readability. Despite these limitations, we believe this study represents a comprehensive overview of survivorship information and accessibility of information on these webpages.

## Conclusions

Information presented on NCI-designated Cancer Center survivorship-focused webpages was inconsistent, often lacking,

**Table 4.** Website Accessibility Checklist for Building Survivorship Websites

<p><b>Who</b> is this information for?</p> <ul style="list-style-type: none"> <li>• Who is your target audience?</li> <li>• How do you define who a cancer survivor is?</li> <li>• Is the language appropriate for that audience?</li> </ul>
<p><b>What</b> are you trying to communicate?</p> <ul style="list-style-type: none"> <li>• Is there a survivorship clinic or a survivorship program?</li> <li>• What resources (if any) are available to cancer survivors?</li> <li>• How do individuals contact you to learn more about these resources?</li> </ul>
<p><b>Where</b> is this information located?</p> <ul style="list-style-type: none"> <li>• Is this information on a webpage for the cancer center or the health care system?</li> <li>• Can you get to this webpage from multiple entry points (ie, from the health care system to a cancer center website, or vice versa)?</li> </ul>
<p><b>When</b> do you expect individuals to access this information?</p> <ul style="list-style-type: none"> <li>• What resources are available for long-term survivors versus individuals completing or undergoing treatment?</li> <li>• How can individuals who didn't receive treatment at your institution access survivorship services?</li> </ul>
<p><b>How</b> is the information presented?</p> <ul style="list-style-type: none"> <li>• Are there clear headers?</li> <li>• What is the reading level of the information?</li> <li>• How is the information organized? Are you using lists, paragraphs, or dropdown menus?</li> <li>• What is the text you are using, and how big is it?</li> <li>• Is the color contrast ratio of the text and background appropriate?</li> <li>• How much text is bolded or italicized?</li> <li>• Do you have images, and if so, are there appropriate alt text descriptions?</li> <li>• How easy is your webpage to navigate and find information on?</li> <li>• Do all the links and buttons work?</li> <li>• Have you checked your website using an online tool like accessScan (<a href="https://accessibe.com/accessscan">https://accessibe.com/accessscan</a>) to evaluate accessibility?</li> </ul>

Abbreviation: alt text, alternative text.

and inaccessible. NCI-designated Cancer Centers are role models for cancer research in the United States and have an obligation to provide survivorship information. Changes to content and website design are needed to provide better information for individuals seeking resources and health information relative to their cancer and care.

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