

original report

Incorporating Multiple Perspectives Into the Development of an Electronic Survivorship Platform for Head and Neck Cancer

abstract **Purpose** To improve the care of survivors of head and neck cancer, we developed the Head and Neck Survivorship Tool: Assessment and Recommendations (HN-STAR). HN-STAR is an electronic platform that incorporates patient-reported outcomes into a clinical decision support tool for use at a survivorship visit. Selections in the clinical decision support tool automatically populate a survivorship care plan (SCP). We aimed to refine HN-STAR by eliciting and incorporating feedback on its ease of use and usefulness.

Methods Human-computer interaction (HCI) experts reviewed HN-STAR using think-aloud testing and the Nielsen Heuristic Checklist. Nurse practitioners (NPs) thought aloud while reviewing the clinical decision support tool and SCP and responded to an interview. Survivors used HN-STAR as part of a routine visit and were interviewed afterward. We analyzed themes from the feedback. We described how we addressed each theme to improve the usability of HN-STAR.

Results Five HCI experts, 10 NPs, and 10 cancer survivors provided complementary usability insight that we categorized into themes of improvements. For ease of use, themes included technical design considerations to enhance user interface, ease of completion of a self-assessment, streamlining text, disruption of the clinic visit, and threshold for symptoms to appear on the SCP. The theme addressing usefulness was efficiency and comprehensiveness of the clinic visit. For each theme, we report revisions to HN-STAR in response to the feedback.

Conclusion HCI experts provided key technical design insights into HN-STAR, whereas NPs and survivors provided usability feedback and clinical perspectives. We incorporated the feedback into the preparation for additional testing of HN-STAR. This method can inform and improve the ease of use and usefulness of the survivorship applications.

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INTRODUCTION

After cancer treatment is complete, survivors need comprehensive ongoing care to address a complex range of needs: detecting and managing persistent and late-developing toxicities (together called late effects), managing comorbidities, monitoring for recurrence and new cancers, and communicating among providers.¹ The provision of survivorship care can be particularly challenging for survivors of head and neck cancer (HNC). Their treatment can cause serious toxicities to the upper aerodigestive tract, which can affect swallowing, speaking, and breathing.²⁻⁸ Chronic alcohol and tobacco use, which are prevalent in this population, contribute to long-term comorbidity.^{5,6,9-13} Survivors also face

ongoing risks of recurrent or new cancers.¹⁴⁻¹⁶ HNC survivors thus require the coordinated involvement of oncology providers, primary care providers, and other specialists.¹⁷

Survivorship care plans (SCPs) are widely promoted as a method to improve care coordination and to enhance the provision of comprehensive survivorship care.¹⁸ SCPs are documents that include a treatment summary and a plan for ongoing care.¹⁸ However, SCPs are notoriously burdensome for oncology providers to create and deliver.¹⁹⁻²³ The burden may be exacerbated for survivors of HNC, who have complicated clinical histories and whose SCPs must address the management of numerous late effects, treatment of comorbidities, modification

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of multiple risk factors, and surveillance for recurrence. To address these challenges, we sought to develop a user-friendly survivorship platform for HNC.²⁴ The Head and Neck Survivorship Tool: Assessment and Recommendations (HN-STAR) uses an electronic platform to facilitate the identification of all late effects and to enable evidence-based care for survivors of HNC. HN-STAR ultimately produces an SCP for survivors and their providers. Our process for developing HN-STAR focused on making it easy to use and useful for both survivors of HNC and their providers. Optimizing HN-STAR positions us to conduct additional research on its effectiveness in coordinating care and promoting late-effects management.

METHODS

Users' perceptions of a technology's ease of use and usefulness influence whether and how they use the technology.²⁵ In developing HN-STAR, we therefore tested key stakeholders' perceptions of the ease of use and usefulness of both the provider-facing and the survivor-facing components of HN-STAR. We refined HN-STAR in response to end-user feedback.

Description of the Platform

HN-STAR is intended for use by patients who have completed treatment of HNC (survivors) and by their providers, before and during routine clinic visits. HN-STAR consists of four components (Fig 1):

(1) HN-STAR generates a Treatment Summary using diagnostic and billing codes. Before the clinic visit, the provider verifies the Treatment Summary against the medical record and corrects any inaccuracies.

(2) Also before the clinic visit, survivors complete the Survivor Self-Assessment, an electronic survey of late effects and health behaviors (Data Supplement). The assessment identifies symptoms using the Patient-Reported Outcomes version of the Common Terminology Criteria for Adverse Events and assesses medical history, preventive health, and behavioral health (eg, depression, alcohol use, and physical activity).²⁶⁻³⁴

(3) HN-STAR integrates responses from the Survivor Self-Assessment and the Treatment

Summary to generate an individualized electronic Clinical Decision Support Tool, which is presented to the provider in clinic to facilitate discussion (Data Supplement). Symptom management composes the bulk of the Clinical Decision Support Tool, with each reported symptom accompanied by diagnoses to consider, recommendations for focused evaluation, and evidence-based management strategies from disease-specific and general medicine literature.^{7,17,35-55} The Clinical Decision Support Tool prompts the provider and the survivor to discuss each symptom and to agree on management strategies, which could include work-up, referrals, follow-up recommendations, prescriptions, self-management suggestions, or education. The provider enters the selected strategies into HN-STAR. Because not all symptoms merit detailed discussion, the provider can opt not to discuss any symptom.

(4) After the provider completes the Clinical Decision Support Tool, HN-STAR generates an SCP. The SCP consists of a treatment summary and management plans for each symptom and health behavior issue. The survivor and primary care provider each receive a printed SCP. The survivor may share the SCP with the oncologist, other providers, family members, and friends. The provider can save the SCP electronically to import into the electronic health record. By collecting symptom reports directly from survivors, HN-STAR ensures that no relevant symptoms are overlooked and enables access to evidence-based symptom management recommendations. HN-STAR automatically creates an SCP as part of the clinic visit, thereby integrating the use of an SCP into the clinical flow. The SCP presents a lay-language treatment summary and explicitly delineates coordination of care for issues discussed in the visit. By directly incorporating current symptoms, the SCP is personalized to the symptoms and risks that are relevant to each survivor. HN-STAR operates independently of any electronic health record to facilitate scalability across clinics. A detailed description of the protocol is provided elsewhere by Salz and colleagues.²⁴

Usability Evaluation

To optimize HN-STAR for additional effectiveness testing, we elicited feedback on HN-STAR from human-computer interaction (HCI) experts,

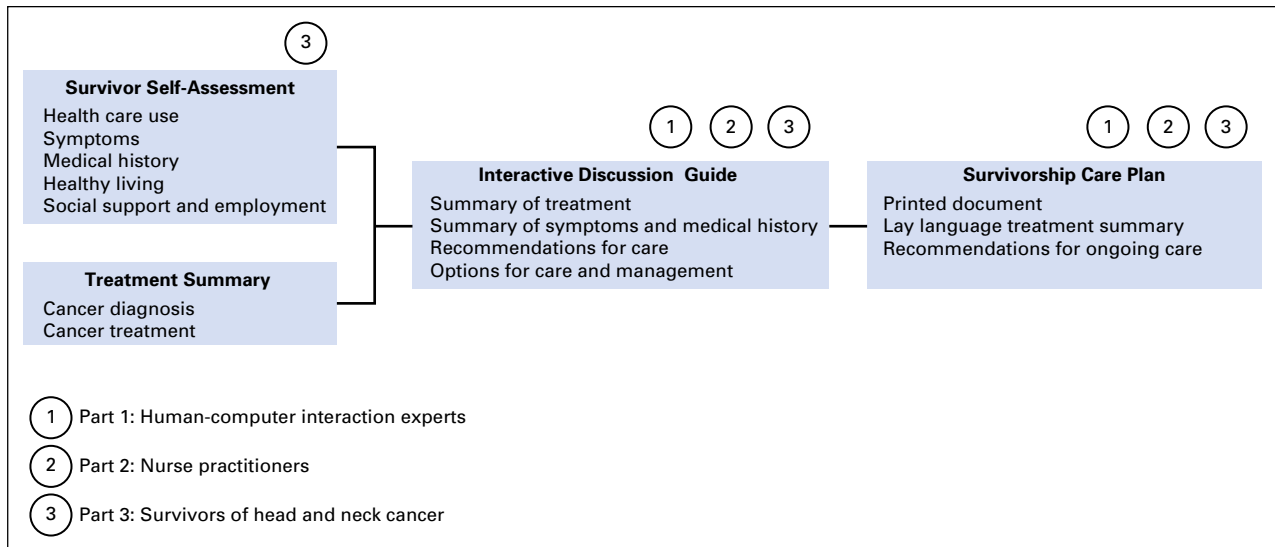


Fig 1. Components of the Head and Neck Survivorship Tool: Assessment and Recommendations and stakeholder assessments.

nurse practitioners (NPs), and survivors of HNC on the Survivor Self-Assessment, the Clinical Decision Support Tool, and the resulting SCP. (Because verification of the Treatment Summary is neither an interactive process nor patient facing, we did not conduct usability testing for this component of HN-STAR.)

HCI Expert Feedback

We invited five HCI experts to assess the two provider-facing components of HN-STAR: the Clinical Decision Support Tool and the SCP. We provided a use case that included a summary of the treatment and symptoms of a mock survivor. Experts were told to use this information to complete the Treatment Checklist and the Clinical Decision Support Tool with minimal instruction. To capture feedback, we used a think-aloud protocol using Morae software (TechSmith, Okemos, MI), which records mouse movements and vocalizations. The HCI experts completed a Usability Checklist derived from Nielsen Heuristics to identify usability issues with the interface.⁵⁶⁻⁵⁸ Ease of use was operationalized in terms of 10 factors, scored from 0 (no usability problem) to 4 (usability catastrophe).

NP Feedback

We engaged NPs from Memorial Sloan Kettering Cancer Center to complete a mock visit using HN-STAR's Clinical Decision Support Tool, with one author (T.S.) playing an HNC survivor. To ensure that HN-STAR would be usable for

providers who do not routinely treat survivors of HNC, we limited this study to NPs who had treated survivors of other cancers. The same Clinical Decision Support Tool was generated for each mock clinic visit. Each visit included the usual practice of taking a medical history. The NPs were asked to think aloud while using the Clinical Decision Support Tool and reviewing the resulting SCP. A research assistant interviewed the NPs about the usability of the HN-STAR interface and the feasibility of its use in clinic. All sessions were audio recorded.

Survivor Feedback

We recruited consecutive English-speaking survivors who were ≥ 3 years from treatment and who were scheduled to visit Memorial Sloan Kettering Cancer Center's HNC survivorship clinic for a routine visit. Before each visit, the survivorship clinic NP (J.M.) verified the Treatment Summary, which populated the Clinical Decision Support Tool. The NP used the Clinical Decision Support Tool on a laptop computer in the clinic. Each participant completed the Survivor Self-Assessment at the clinic and was interviewed immediately regarding that experience. After the visit, the printed SCP was provided to the survivor. Each survivor was interviewed about the visit and the SCP. This study received institutional review board approval. Each survivor provided informed consent.

Table 1. Nurse Practitioner Characteristics (n = 10)

| Characteristic | Nurse Practitioners |
|--|---------------------|
| Age, years, mean (range) | 41 (31-58) |
| Years in practice in survivorship clinic(s), mean (range) | 5 (1-11) |
| Years since training, mean (range) | 12 (5-24) |
| Female, No. (%) | 10 (100) |
| Ever use a computer in a clinic visit, No. (%) | 6 (60) |
| Very comfortable or comfortable with electronic medical records, No. (%) | 9 (90) |
| Very comfortable or comfortable with computers in general, No. (%) | 10 (100) |

Analysis

We integrated feedback from HCI experts, NPs, and survivors regarding features and functionality. We calculated descriptive statistics for each of the usability factors for the Nielsen Heuristics Checklist completed by HCI experts. We used the usability factors to code data from HCI experts' comments on the Nielsen Heuristics Checklist and the NPs' think-aloud comments. We qualitatively analyzed feedback from survivors and NPs and organized them by theme under the categories of ease of use and usefulness. This approach revealed opportunities for addressing users' needs and for optimizing HN-STAR for future testing.

RESULTS

Sample

The five HCI informatics experts had completed at least a master's degree in clinical informatics. The 10 NPs had been in practice in survivorship clinics for 5 years, on average, and all were comfortable or very comfortable with computers (Table 1). The 10 survivors had a range of sites of disease within the head and neck. The average age was 60 years; 90% were male; and 80% were either comfortable or very comfortable with computers (Table 2). Survivors took 22 minutes, on average, to complete the Survivor Self-Assessment. The average duration of clinic visits, which included a physical examination and cancer surveillance in addition to the HN-STAR-guided discussion, was 63 minutes. After 10 mock clinic visits and 10 survivor interviews, we reached thematic saturation.

Ease of Use

Technical design considerations for user interface. Table 3 presents usability factor scores and summarized feedback from HCI experts and NPs. HCI experts' mean ratings on the Nielsen Heuristics Checklist ranged from 1.0 (cosmetic problem only) to 2.7 (between minor and major usability problem). Think-aloud responses from NPs described usability issues across all usability factor categories, with the category of Flexibility and Efficiency of Use containing the greatest number of issues. The HCI experts' comments on the Heuristic Evaluation Checklist identified opportunities to refine some of the technical aspects of HN-STAR. Both HCI experts and NPs suggested using clearer icons and headers and making fields easier to find. HCI experts offered more technical critiques than did NPs; these included suggesting a more intuitive use of color and a more standard indicator for required fields. NPs provided technical feedback that addressed the clinical context of HN-STAR. For example, NPs wanted text boxes to insert additional details

Table 2. Patient Characteristics (n = 10)

| Characteristic | Patients |
|--|--------------|
| Age, years, mean (range) | 60 (51-70) |
| Years since diagnosis, mean (range) | 7 (4.5-11.6) |
| Non-Hispanic white, No. (%) | 10 (100) |
| Male, No. (%) | 9 (90) |
| Histology, No. (%) | |
| Oropharynx | 5 (50) |
| Oral cavity | 2 (20) |
| Hypopharynx | 1 (10) |
| Larynx | 1 (10) |
| No primary site | 1 (10) |
| Stage, No. (%) | |
| I | 2 (20) |
| II | 0 (0) |
| III | 5 (50) |
| IVA | 3 (30) |
| IVB | 0 (0) |
| HPV positive status, No. (%) | 3 (30) |
| Treatment, No. (%) | |
| Surgery | 5 (50) |
| Radiation | 9 (90) |
| Chemotherapy | 8 (80) |
| Comfortable or very comfortable using computers, No. (%) | 8 (80) |

Abbreviation: HPV, human papillomavirus.

Table 3. Violations of Usability Heuristics Noted by Human-Computer Interaction Experts and NPs

| Usability Factor | Overall Mean (SD) | Summarized Comments About Clinical Decision Support Tool and Survivorship Care Plan | |
|---|-------------------|--|--|
| | | Clinical Informatics Experts (from heuristic checklist) | NPs (from think-aloud testing) |
| Visibility of system status | 1.6 (1.14) | <p>Clinical Decision Support Tool:</p> <p>Some hidden options were hard to find.</p> <p>Indication of location would benefit from progress bar.</p> <p>Screen headers need clarification.</p> <p>Red highlighted text looked like a button.</p> <p>A check box was required before entering text into a text field, which required too many clicks.</p> | <p>Clinical Decision Support Tool:</p> <p>A page about radiation effects was confusing, because it was unclear if it was for all patients who received radiation or only for those who reported symptoms from radiation.</p> <p>The headers did not clarify the distinction between recommendations and referrals (eg, for mammograms).</p> <p>The end of the Clinical Decision Support Tool was abrupt.</p> <p>Survivorship Care Plan:</p> <p>There is a Print button on the Survivorship Care Plan care plan that does not result in printing.</p> |
| Match between system and the real world | 1.4 (1.34) | <p>Clinical Decision Support Tool:</p> <p>It was unclear what data were entered by patient and how sections were organized.</p> | <p>Clinical Decision Support Tool:</p> <p>The fixed order of pages addressing symptoms and other topics did not reflect the typical order of clinical visits, particularly the order of symptoms, the grouping of lifestyle behaviors, and when the summary of other providers and patient weight are presented.</p> <p>Actions required for sections of the symptom pages entitled “Not discussed” and “Common diagnosis” were unclear.</p> <p>There was no place to describe details of symptoms.</p> |
| User control and freedom | 2.2 (1.3) | <p>Clinical Decision Support Tool:</p> <p>Patient-filled boxes cannot be modified.</p> <p>Survivorship Care Plan:</p> <p>Once the Survivorship Care Plan is created, it is impossible to go back.</p> | <p>Clinical Decision Support Tool:</p> <p>The “Menu” button did not return the NP to the previous page as expected.</p> <p>The Clinical Decision Support Tool does not allow skipping between topics, as is preferred in a typical visit.</p> <p>There was no easy way to move back and forth from examining the patient to using the computer.</p> |

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about symptoms. Survivors, in turn, commented on the visual design of the SCP. They suggested improving the plan’s readability, including using less narrative text and using color for emphasis. In response, we altered the design of HN-STAR to better engage and guide users. For example, in the Clinical Decision Support Tool, we reserved the color red for situations in which an alert was needed; we used a green background to indicate sections that users must complete. Asterisks were added to draw attention to required responses, and a menu button was added to facilitate navigation. We made the SCP more readable by increasing the use of bullet points and by adding color.

Ease of completion of the Survivor Self-Assessment. Table 4 presents selected quotes from survivors

and NPs illustrating themes regarding the ease of use of HN-STAR. Survivors reported no difficulty in completing the Survivor Self-Assessment. However, they noticed that certain symptoms were not addressed. To fix this, we added an explanation about how survivors can enter information about any remaining symptoms.

Streamlining text. HCI experts, NPs, and survivors agreed that text should be limited in various parts of HN-STAR. Specifically, the NPs noted that pages addressing cancer screening in the Clinical Decision Support Tool were unnecessarily long. Similarly, survivors and NPs thought the SCP was too long and they suggested areas to condense. In response, we streamlined the text in the Clinical Decision Support Tool, especially

Table 3. Violations of Usability Heuristics Noted by Human-Computer Interaction Experts and NPs (Continued)

| Usability Factor | Overall Mean (SD) | Summarized Comments About Clinical Decision Support Tool and Survivorship Care Plan | |
|--|-------------------|---|--|
| | | Clinical Informatics Experts (from heuristic checklist) | NPs (from think-aloud testing) |
| Consistency and standards | 1.2 (1.3) | <p>Clinical Decision Support Tool: Green is not reserved to indicate action. Text could be more compact to avoid scrolling. Colors are distracting. Important information about age is too far down on one screen.</p> | <p>Clinical Decision Support Tool: The distinction between two text boxes on each symptom page was unclear. There is a text box to indicate any concern not addressed previously, but it is not consistent with the other pages, and the instructions were wordy and unclear. If the patient answered questions suggesting he or she had problems with sexual health, but also selected the option not to discuss sex, it was unclear how to proceed. After the depression screen, the recommendation options appear on the following page, which is different from all the rest of the symptom pages, in which the recommendations are on the same page as the symptom description. On each of the screening pages for different types of cancers, the definition of high risk was indicated; however, it was unclear that this information was not tailored to the patient. Although we do not assess family history of cancer, the screening pages describe risk as a result of family history. The NPs were confused about how to make an appropriate recommendation.</p> |
| Helps users recognize, diagnose, and recover from errors | 1.0 (1.41) | | <p>Clinical Decision Support Tool: If a mandatory question was skipped, a pop-up box appeared. Red text indicated both questions that patients did not answer and questions that the NP needed to answer. This was confusing because patient responses are not editable.</p> |
| Error prevention | 2.0 (1.41) | <p>Clinical Decision Support Tool: Comment fields could not accept returns, so all entries appear on the same line. Medication list should be structured.</p> | <p>Clinical Decision Support Tool: There were too many check boxes in the physical activity section, resulting in some missed responses. Navigating back from the Menu was difficult. One option for smoking cessation was available as a selection but is not available to patients at one hospital. To create the Survivorship Care Plan, there is a button called "Delivered on" that prompts the NP to select a date on a calendar. The wording is confusing, and the section was also easy to miss.</p> |
| Recognition rather than recall | 1.8 (1.3) | <p>Clinical Decision Support Tool: Headings on some pages are not clear. There was too much color.</p> | <p>Clinical Decision Support Tool: The way to expanding section on Focused Evaluation was to click on an icon, which NPs did not recognize.</p> |

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Table 3. Violations of Usability Heuristics Noted by Human-Computer Interaction Experts and NPs (Continued)

| Usability Factor | Overall Mean (SD) | Summarized Comments About Clinical Decision Support Tool and Survivorship Care Plan | |
|-----------------------------------|-------------------|--|--|
| | | Clinical Informatics Experts (from heuristic checklist) | NPs (from think-aloud testing) |
| Flexibility and efficiency of use | 1.2 (1.79) | <p>Clinical Decision Support Tool:</p> <p>There was no usable menu to skip around.</p> | <p>Clinical Decision Support Tool:</p> <p>Pressing “enter” within text boxes did not result in creating different lines.</p> <p>There are no text boxes for the NP to write notes for his or her own information that would not appear on the Survivorship Care Plan.</p> <p>There was no integration with the medical record to reduce charting afterward.</p> <p>There was limited ability to skip around.</p> <p>There is no function to import existing medication information from the current patient record. Alternatively, a dedicated space to include dosage, frequency, and prescriber would be useful.</p> <p>There is no place to add another symptom management option when there was none available they wanted to select.</p> <p>When an NP wants to provide online resources to a patient about physical activity, the NP is required to first select the “physical activity discussed” option and select a specific type of online resource.</p> <p>All cancer screening was listed together rather than having a separate box for each cancer.</p> <p>There were too many things to click throughout the Clinical Decision Support Tool. However, the NPs also mentioned that clicking is much easier to do than typing free text while trying to engage with a patient.</p> <p>Survivorship Care Plan:</p> <p>The Survivorship Care Plan does not have an electronic format to enable access to the online resources. Nor could the NP easily print the suggested resources automatically.</p> |
| Aesthetic and minimalist design | 1.4 (1.34) | <p>Clinical Decision Support Tool and Survivorship Care Plan:</p> <p>There were too many words.</p> | <p>Clinical Decision Support Tool:</p> <p>A blank line was meant to indicate when something was unanswered by the patient, and many NPs erroneously clicked that line to try to fill it in.</p> <p>The page addressing depression is wordy.</p> <p>For lung cancer screening, there is unnecessary information about tobacco use.</p> <p>The screening pages were too wordy.</p> <p>The section addressing physical activity appears twice for patients.</p> |
| Help and documentation | 2.7 (0.58) | <p>Clinical Decision Support Tool:</p> <p>There is no help menu.</p> | |

NOTE. Human-computer interaction experts (n = 5) and NPs (n = 10). Violations ranged from 0 (no usability problem) to 4 (usability catastrophe). Abbreviations: NP, nurse practitioner; SD, standard deviation.

Table 4. Selected Quotations From Survivors and NPs Regarding Ease of Use of HN-STAR

| Ease of Use Quotation | Survivor | NP |
|--|---|--|
| Ease of completion of the Survivor Self-Assessment | <p>[The Assessment included] simple, straightforward questions that are pertinent to this type of cancer.</p> <p>I could get though it easily. ...It was pretty straightforward once you get used to the clicking.</p> <p>I think if you have access to a computer it would be very, very easy to do this at home.</p> <p>It was similar to what we normally fill out by hand when we come in for a visit.</p> <p>The one thing I want to talk to [the NP] about is a feeling I'm having in my ear and on the side of my face and neck where I had my surgery.</p> <p>I know I lost my taste because of the treatments, and it didn't ask that.</p> <p>[The Assessment included] simple, straightforward questions that are pertinent to this type of cancer.</p> | |
| Streamlining text | <p>If you could consolidate this or aggregate certain related topics [in the SCP], I think you'd be better off.</p> <p>Rather than me going online and accessing [information], if something was bothering me or if I had a question, I'm going to call. Versus going online, I would call.</p> <p>I'm kind of a believer in you can't have too much information ... I thought [the SCP] was good. I thought it was the right amount of information in there.</p> <p>If you could consolidate this or aggregate certain related topics [in the SCP], I think you'd be better off.</p> | I think there's some things in [the SCP] that maybe don't need to be on here. |
| Disruption of the clinic visit | <p>[The NP] has to go from the computer back to me back to the computer back to me back to the computer and...she felt, and I think I felt it too, that she should be spending less time looking at the computer and spend more time working with me</p> | <p>It was pretty easy to figure out. Especially being the first time I looked at it.</p> <p>The [Clinical Decision Support Tool] was easy to use ... With more training I would feel that it's [even easier].</p> <p>I think that using the computer in clinic ... wouldn't allow me to direct the visit and move things along as I typically do.</p> <p>It seems like it distracts me from the patient.</p> <p>The order [of symptoms addressed in a typical visit]...can vary. Sometimes it just starts with the patient telling you what's most troubling to them. Even though it's not in your typical systems order. So sometimes it will start there and you just have to go with that, and [with HN-STAR] you'll have to backtrack.</p> <p>As long as [the Clinical Decision Support Tool] is addressing everything the patient is concerned about, I don't think the order necessarily matters because you're still getting to everything.</p> |

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Table 4. Selected Quotations From Survivors and NPs Regarding Ease of Use of HN-STAR (Continued)

| Ease of Use Quotation | Survivor | NP |
|---|----------|---|
| Threshold for symptoms to appear on SCP | | When patients complete those sorts of self-report tools in clinic, ...they'll mark yes to everything. And I'll address them, certainly, but I don't think they need to go into the [SCP]. Like numbness: you ask them about it and... 'Well, three years ago I felt numbness in my hand for a little, but it just went away and it's never happened again.' ... So if there was a way to really just make sure [the SCPs] include just the actually pertinent things that are treatment related, that we want to continue to follow or look out for... |

NOTE. Survivors (n = 10) and NPs (n = 10).

Abbreviations: HN-STAR, Head and Neck Survivorship Tool: Assessment and Recommendations; NP, nurse practitioner; SCP, survivorship care plan.

limiting the level of detail in recommendations under the purview of other providers. This change will shorten the Clinical Decision Support Tool and generate more concise SCPs.

Disruption of the clinic visit. NPs agreed that learning to use the Clinical Decision Support Tool was easy, although some felt that using the computer in clinic was disruptive. Some survivors also disliked NPs shifting attention between the computer and the survivor. The process of displaying each symptom in a predetermined order also disrupted the NPs' usual practice styles. As NPs proceeded through the mock visits, they were unaware of which symptoms, or how many symptoms, they would be shown. To minimize disruption, we revised the Clinical Decision Support Tool to begin with a summary screen listing all reported symptoms. This alerts the NP to the symptoms that require attention; the symptom list also facilitates a physical examination that addresses each symptom. In addition, the summary screen enables the NP to pace the visit and to ensure that all important issues are covered, particularly if there is a long list of problems.

Threshold for symptoms to appear on SCP. Every symptom that a survivor reports in the Survivor Self-Assessment appears in the Clinical Decision Support Tool and SCP. However, NPs reported that some symptoms reported by survivors are unrelated to their cancer and should not appear on the SCP, because they distract from more salient treatment-related toxicities. We used this feedback to give NPs more control in addressing symptoms. We added a feature to the Clinical Decision Support Tool to allow NPs to omit unrelated or unimportant symptoms from the resulting SCP. This improvement also reduces the amount of text in the SCP.

Usefulness

Survivors and NPs offered largely positive feedback about the usefulness of HN-STAR (Table 5). NPs appreciated how the SCP could improve care coordination by including information regarding other providers involved in the survivor's care. Survivors, in turn, saw the SCP as a helpful record of the visit. Survivors reported that the Survivor Self-Assessment would make visits more efficient by reducing the forms to fill out in advance and by guiding them to think about their needs in preparation for a visit. NPs noted that using the Clinical Decision Support Tool facilitated the conduct of a comprehensive visit. Survivors agreed that the visit was comprehensive and informative. NPs welcomed the potential for the SCP to reduce visit documentation by using electronic symptom reporting and having a summary of actions from the visit in the SCP. However, there were concerns that documentation from HN-STAR would not replace the clinical note required for billing. To reduce duplicative work, we added a free-text field to every screen, in which the NP can type notes that can be cut and pasted into the electronic medical record.

DISCUSSION

The multitude of issues complex cancer survivors experience complicates the provision of survivorship care and SCPs. HN-STAR was designed to facilitate the dissemination of SCPs to improve care coordination and to facilitate late-effects management among HNC survivors. Our goal was to develop a platform that minimized implementation challenges so that we could advance a strong survivorship intervention for additional evaluation. To this end, we assessed ease of use

Table 5. Selected Quotations From Survivors and NPs Regarding Usefulness of HN-STAR

| Usefulness Quotation | NP | Survivor |
|--|---|--|
| Overall | <p>I liked that [the SCP] delineated what should be done by the primary care doctor versus what's done by survivorship [teams].</p> <p>For me, this outside provider piece is huge, so just having the detail clear there...I always check to see if they have an external provider first just because so much of [their care] has to do with primary care.</p> | <p>I really like [the SCP]. I really like that I can walk out of here with all the notes from what I talked about. I just think it's very organized. Normally, I would go home and write my own notes in my own little medical file, and now I have it all done for me.</p> <p>[The SCP] is good because now we can go back and review it, and it will reinforce what we went through.</p> |
| Efficiency and comprehensiveness of the clinic visit | <p>I used to fill out a form, and then go in and repeat the stuff. I'm sure they can review this beforehand, before the visit, and I think that makes it more efficient, and it's probably easier to read the handwriting on the survey online.</p> <p>I also think it's nice to have this done ahead of time.</p> <p>I liked it. I thought it was really easy to use and kind of nice to get your thoughts together ahead of the visit.</p> <p>[HN-STAR] encouraged more dialogue.</p> <p>[The visit] was helpful and informative.</p> <p>[The visit] was helpful, and I liked the plan.</p> | <p>It was comprehensive... [The Clinical Decision Support Tool] is exactly what I cover in my visits, and it covered everything that I typically do—maybe a little bit more.</p> <p>I liked having all the standardized ... interventions and recommendations for patient [education] or follow-up and everything right there.</p> <p>I think there's real benefit...in being able to do this as you go through [the visit]. Because I spend so much time charting afterward and if I could somehow integrate it, it would be awesome. So I like the idea.</p> |

NOTE. Survivors (n = 10) and NPs (n = 10).

Abbreviations: HN-STAR, Head and Neck Survivorship Tool: Assessment and Recommendations; NP, nurse practitioner; SCP, survivorship care plan.

and usefulness from the perspectives of multiple stakeholders. HCI experts brought attention to the technical design aspects of HN-STAR. They found it easy to use overall, and they highlighted usability issues that we were able to address in almost all cases. NPs demonstrated how HN-STAR needed adaptation to function in a clinical setting. Survivors provided feedback on making the computer interface user friendly and on adapting HN-STAR to improve the clinic experience. We incorporated these insights into improvements in HN-STAR, enhancing its ease of use and usefulness for survivors and NPs.

Our study has several limitations. It involved a single refinement of HN-STAR; a more iterative process could involve adapting HN-STAR numerous times in response to feedback.⁵⁹ By design, HN-STAR functions independently of any electronic health record platform. However, for providers who use an electronic health record in clinic, having a separate computer interface for the Clinical Decision Support Tool may decrease ease of use. We limited participation to English-speaking survivors, and most were comfortable using computers. Furthermore, our

edits to HN-STAR were based on NPs and a survivor population in a large cancer center, and we did not elicit usability feedback about the SCP from primary care providers. HN-STAR has the capacity to track symptoms over time; however, we tested usability at a single clinic visit only. Future studies should examine feasibility in multiple survivorship clinics, should include the perspectives of diverse survivors and primary care providers, and should test the usability of longitudinal symptom tracking.

Previous research on SCPs has yielded null results with respect to improving the processes and outcomes of survivorship care.⁶⁰⁻⁶⁴ A critique of existing trials is a lack of reporting on implementation details, and it is therefore unclear whether null findings indicate poor SCP effectiveness or poor clinical implementation of SCPs.⁶⁵ It is vital to focus on the metrics of ease of use and usefulness during development, to increase the chance of smooth implementation. By integrating systematically elicited insights from multiple end users into a revised version of HN-STAR, we aim to increase uptake of and engagement with HN-STAR in future studies.

An improved HN-STAR is more likely to demonstrate improved care coordination and late-effects management.

Although other studies have investigated survivors' and physicians' responses to and need for SCPs, to our knowledge, this is the first study to gather systematic stakeholder feedback to inform the early development and implementation of an SCP. Moreover, there has been little work evaluating SCPs for people with HNC, and our study adds to that literature.^{66,67} Our findings suggest that incorporating electronic patient-reported outcomes (and accompanying recommendations) into clinical practice for cancer survivors can benefit from usability and feasibility testing. There is growing evidence that eliciting symptoms from survivors and reporting directly to providers will improve the accuracy of assessment, quality of care, and health outcomes (including survival), but to our knowledge this has never been tested in ongoing cancer survivorship care.^{26,68-72} Assessing the usability and feasibility of presenting symptom reports with accompanying evidence-based recommendations is critical as health systems move forward with the integration of patient-reported outcomes into clinical practice.

Our usability study identified important end points to consider when testing the feasibility, implementation, and effectiveness of HN-STAR. For example, survivors in our study reported being receptive to entering their health information online at the clinic, but future testing will elucidate to what extent survivors complete this testing at home before their clinic visit. For NPs, feasibility testing must assess whether NPs use the newly added features of the platform to streamline their documentation. The shortened SCP will be assessed in terms of whether it is given to the survivor, whether the NP discusses it in clinic, and whether the survivor finds the information trustworthy and useful. This study to optimize HN-STAR for additional testing is an important first step in improving the care of survivors of complex cancer, where provision of ongoing care and delivery of SCPs can be especially difficult. Usability testing enabled us to shape the content and delivery of HN-STAR in response to expert and end-user feedback, creating a robust clinical platform for additional clinical testing.

DOI: <https://doi.org/10.1200/CCI.17.00105>

Published online on ascopubs.org/journal/cci on February 21, 2018.

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matter of this manuscript. For more information about ASCO's conflict of interest policy, please refer to www.asco.org/rwc or ascopubs.org/jco/site/ifc.

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Consulting or Advisory Role: IBM Watson Oncology

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AUTHOR'S DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

The following represents disclosure information provided by authors of this manuscript. All relationships are considered compensated. Relationships are self-held unless noted. I = Immediate Family Member, Inst = My Institution. Relationships may not relate to the subject

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No relationship to disclose

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Travel, Accommodations, Expenses: Memorial Sloan Kettering Cancer Center

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Patents, Royalties, Other Intellectual Property: Bristol-Myers Squibb (Inst), AstraZeneca (Inst)
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Support

Supported by Grant CA187441 (S.B. and T.S.) and P30 Cancer Center Support Grant P30 CA008748 from the National Institutes of Health (Memorial Sloan Kettering).

Prior Presentation

Presented as a poster at the Biennial Cancer Survivorship Symposium, Washington, DC, June 16-18, 2016 and as an abstract at the ASCO Annual Meeting, Chicago, IL, June 1-5, 2017.

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