

Translating an Economic Analysis into a Tool for Public Health Resource Allocation in Cancer Survivorship

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Abstract

Background. The complexity of decision science models may prevent their use to assist in decision making. User-centered design (UCD) principles provide an opportunity to engage end users in model development and refinement, potentially reducing complexity and increasing model utilization in a practical setting. We report our experiences with UCD to develop a modeling tool for cancer control planners evaluating cancer survivorship interventions. **Design.** Using UCD principles (described in the article), we developed a dynamic cohort model of cancer survivorship for individuals with female breast, colorectal, lung, and prostate cancer over 10 y. Parameters were obtained from the National Program of Cancer Registries and peer-reviewed literature, with model outcomes captured in quality-adjusted life-years and net monetary benefit. Prototyping and iteration were conducted with structured focus groups involving state cancer control planners and staff from the Centers for Disease Control and Prevention and the American Public Health Association. **Results.** Initial feedback highlighted model complexity and unclear purpose as barriers to end user uptake. Revisions addressed complexity by simplifying model input requirements, providing clear examples of input types, and reducing complex language. Wording was added to the results page to explain the interpretation of results. After these updates, feedback demonstrated that end users more clearly understood how to use and apply the model for cancer survivorship resource allocation tasks. **Conclusions.** A UCD approach identified challenges faced by end users in integrating a decision aid into their workflow. This approach created collaboration between modelers and end users, tailoring revisions to meet the needs of the users. Future models developed for individuals without a decision science background could leverage UCD to ensure the model meets the needs of the intended audience.

Highlights

- Model complexity and unclear purpose are 2 barriers that prevent lay users from integrating decision science tools into their workflow.
- Modelers could integrate the user-centered design framework when developing a model for lay users to reduce complexity and ensure the model meets the needs of the users.

Keywords

cost-effectiveness, cancer survivorship, User Centered Design, resource allocation, decision model, willingness to pay, quality of life

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The number of persons who have received a cancer diagnosis (cancer survivors) is rapidly increasing in the United States due to the growth in the number of older adults and improvements in screening, treatment, and supportive care.^{1,2} Publicly funded cancer control programs are interested in using evidence-based approaches to support people who have survived cancer.³ There is a need for quantitative tools to help decision makers select these approaches while operating within resource constraints. In a 2012 study, most state/Pacific Island/tribal/territorial-level cancer control program directors expressed a need for assistance in assessing and using evidence-based resources for this population.⁴ This survey also found that the cancer control planning directors felt that limited resources (e.g., financial, evidence-based information, etc.) were a significant barrier to adopting evidence-based practices for their populations. A cost-effectiveness model framework may provide a quantitative tool to aid public health officials in resource allocation as well as in exploring the impact of programs for cancer survivors. Currently, there are no cost-benefit decision tools available to aid decision makers in resource allocation decisions and in understanding the impact (in terms of net monetary benefit) of doing a cancer survivorship intervention versus no intervention.

In response to these needs, we used a multistep, audience-informed process using focus groups based on user-centered design to build a cost-effectiveness decision tool for decision makers and cancer control planners that target end users. User-centered design is a process that integrates end users throughout the design process to increase the usability of the final product.⁵ Focus

groups allow model designers an opportunity to explore contextual factors and solicit feedback or ideas from users about a theme, concept, or product. This type of qualitative data collection has been used in market research and product development as well as the public health space.^{6,7} In the product development literature, focus groups are viewed as an approach that identifies issues that end-users experience when using the product. The authors spoke with partners from the American Public Health Association (APHA), Centers for Disease Control and Prevention (CDC), and a group of state-level cancer control planners to explore common challenges that cancer control planners face in implementing evidence-based survivorship interventions and their perspectives on the use of a cost-effectiveness tool. The objective of this article is to report on the user-centered design process and to offer lessons learned for future developers.

Methods

Overview

We followed user-centered design principles (<https://www.usability.gov/what-and-why/user-centered-design.html>) to construct this cost-effectiveness model as opposed to a noniterative, waterfall modeling approach, moving through the steps of ideation, prototyping, and iteration to arrive at a design solution (Figure 1).⁵ Ideation involved defining the model parameters with the modeling team from Fred Hutchinson Cancer Center, APHA, and the CDC. This step also involved identifying the target end users, the intended use, and overall goals of the model/tool. Prototyping included the process of building the model from a basic concept to a complete design. And the iteration stage was defined by usability testing with actual users and the continuous evaluation and improvement process. Prototyping and iteration occurred through focus groups, with the initial prototyping and iteration step engaging end users at the state cancer control level and the second iteration step engaging users at the national organization level.

Ideation

Model structure. We constructed a model in Microsoft Excel™ to simulate health outcomes and costs of a variety of postcancer diagnosis survivorship interventions (e.g., smoking cessation, psychological counseling, cancer surveillance, dietary modifications, and physical activity), described in more detail in the Appendix. The model was designed to compare the impact of different cancer

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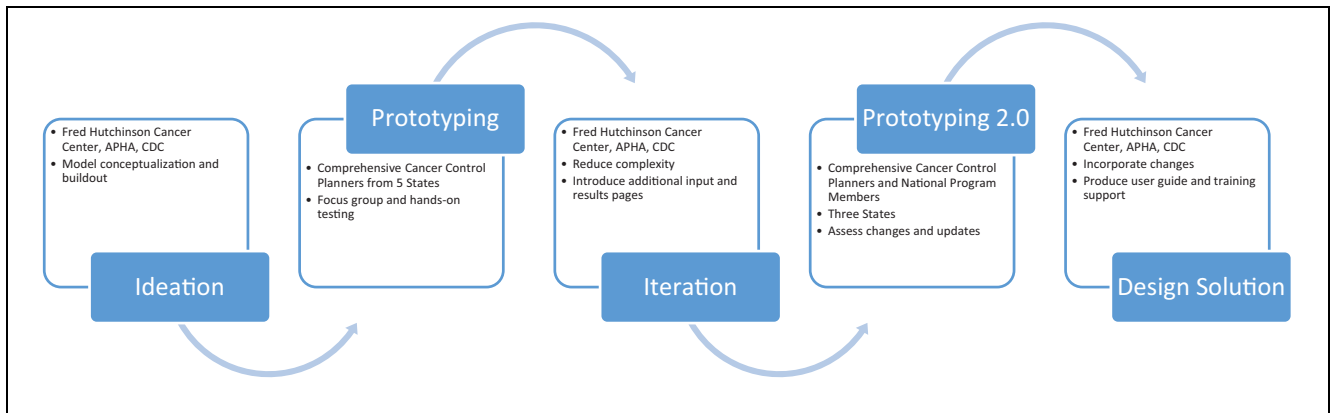


Figure 1 Feedback and revision framework. APHA, American Public Health Association; CDC, Centers for Disease Control and Prevention; Fred Hutchinson Cancer Center. Feedback and revision framework adapted from User-Centered Design Basics: Usability.gov (<https://www.usability.gov/what-and-why/user-centered-design.html>).

survivorship interventions with the current standard of care to assess the value of implementing these interventions. Our decision model follows a dynamic cohort of cancer survivors diagnosed with female breast, colorectal, lung, or prostate cancer over a 10-y time horizon (2006–2016). These cancers were selected because they are the top 4 cancers, excluding skin cancer, occurring among men and women and accounting for approximately half of all new cancer cases per year.¹ For this study, cancer survivors were defined as those alive 1 y after diagnosis and were assigned to a survivorship intervention or the status quo standard of care. The primary outcome compares the economic return of the survivorship intervention strategy (in net monetary benefit) versus the status quo care. The model takes the US national perspective, with options for state-based stratification, and spans a 10-y time frame. We used a dynamic modeling approach, which identifies and models new cohorts of cancer survivors in each year of the model time horizon. The willingness-to-pay threshold was set at \$100,000 per quality-adjusted life-year (QALY), as public health interventions that cost less than \$100,000 per QALY are generally considered as cost-effective.⁸ Costs and QALYs are discounted at a 3% annual rate.

Key model input parameters were derived from central cancer registries and peer-reviewed literature assessing the impact of various interventions.^{9–12} Input parameters are also customizable based on users' expertise, experience, or specific program. State-level incidence and survival data were obtained from the CDC's National Program of Cancer Registries (NPCR).¹ Due to the granularity of survival data needed, proxy states were used for states where data were not available due to data use agreement,

for example, Connecticut (proxy = Massachusetts), Hawaii (proxy = Florida), Indiana (proxy = Missouri), Iowa (proxy = Nebraska), Kansas (proxy = Nebraska), Minnesota (proxy = Wisconsin), New Mexico (proxy = Arizona), Nevada (proxy = Arizona), and South Dakota (proxy = North Dakota). For the states where NPCR data were not available, we assumed a similar annualized incidence and survival outcomes for neighboring states with similar sociodemographic composition (indicated in parentheses).

Survivorship interventions considered for this model were selected based on available literature and on potential for high impact, uptake, or perceived need.^{13–26} The interventions include smoking cessation, psychological counseling, dietary changes, physical activity, and cancer surveillance.^{13–26} These interventions are described in the Appendix along with detailed discussions on other key cost and utility input parameters of the model including base annual health expenditure per patient, annual cost of the intervention per patient, change in survival for patients who received the intervention, base health state utility for cancer survivors, and impact of intervention on health state utility.

Model outcomes included change in incident cancer cases, change in total and QALYs, change in direct monetary expenditure, and change in net monetary benefit. Each outcome was represented as the number of events or amount of money or life-years accrued under the standard of care and intervention arms as well as the amount gained or lost when the intervention was implemented. QALYs were calculated by multiplying the total number of life-years accrued in each health state by their corresponding health-state utility value derived from the

literature (details are described in the Appendix). Direct monetary expenditure was calculated as the annual amount spent on cancer and noncancer health care, increased or decreased by the cost and potential financial benefits of the intervention. Net monetary benefit was calculated by converting the QALYs accrued over the time horizon into a dollar amount using the willingness-to-pay threshold and incorporating the direct health care costs incurred over the time horizon into a final dollar amount. The model outcome can help decision makers in any US state or jurisdiction ascertain the net benefit (in terms of life-years, QALYs), net costs (direct monetary expenditures) and net monetary benefit of doing a cancer survivorship intervention versus no intervention over a 10-y time horizon.

Design framework. The first version of the model's user interface allowed maximum user customization of various inputs parameters (Figure 2). The input tab included options for user-directed assumptions about discounting and willingness-to-pay thresholds and granular custom inputs for each stage (local, regional, distant)²⁷ of each cancer site (female breast, colorectal, lung, and prostate), for hazard ratios, health state utility changes, and medical expenditures, resulting in 18 different user-customizable input values for each of the cancer sites. This level of customization was selected to allow end users to identify features they felt were important, as well as features that were unlikely to be used in day-to-day use. All model results were displayed on 1 tab/worksheet in a graphical and tabular format (Figure 3).

Prototyping

Participants and partners. State-level focus group participants ($n = 7$) were recruited through CDC's National Comprehensive Cancer Control Program (NCCCP; group 1). Group 1 participants were identified from award recipients of CDC's request for proposal on "Increasing the Implementation of Evidence-Based Cancer Survivorship Interventions to Increase Quality and Duration of Life among Cancer Patients."²⁸ These participants were chosen based on their leadership roles in the state's comprehensive cancer control program and interests in implementing evidence-based cancer survivorship programs. Fred Hutchinson Cancer Research consented participants prior to the online focus group sessions. Participants from CDC (group 2) were recruited from among the author's colleagues and had different

academic disciplines and positions: epidemiologists, health services researchers, economists, program consultants, and public health analysts. This research was found to be exempt from Institutional Review Board review by Fred Hutchinson Cancer Center.

Feedback solicitation. We engaged potential users in the prototyping and iteration portion of the design process (Figure 1). The first round of users (group 1) included the NCCCP participants. Prior to the first session, we provided participants with the questions listed in Table 1. During the first session, we presented the study objective, described the model inputs and outputs, and demonstrated how to use the model. Participants provided verbal feedback during the session on questions from the premeeting handout. Two members of the modeling team led these discussions, with a third member taking notes regarding feedback provided.

After this session, we distributed the model and a user guide that contained specifics on how to navigate the model. Users were provided with questions focused on the model's usefulness, accessibility, and time frame (Table 2). Users were given 2 wk to review the model and provide feedback to the modeling team.

Iteration

Feedback from each focus group session was discussed among the modeling team. Feedback was clustered into informal themes through a discussion process, identifying similar challenges and potential changes raised by each end user. Mock-up models were distributed among the modeling team in between each session, to illustrate multiple approaches addressing feedback from focus group participants (both group 1 and group 2). Final decisions for updated model designs were accepted based on consensus from most modeling team members. Updated models were distributed to state-level end users for a second wave of focus groups, with feedback being collected via unstructured email responses. Themes and improvements were identified from this feedback and used to produce another iteration of the model. This model was used to conduct focus group sessions with CDC NCCCP leadership (group 2). These focus groups followed a similar approach to the state-level groups, identifying themes and updating the model based on feedback received in the first group and validating the usefulness of the changes with the second group.

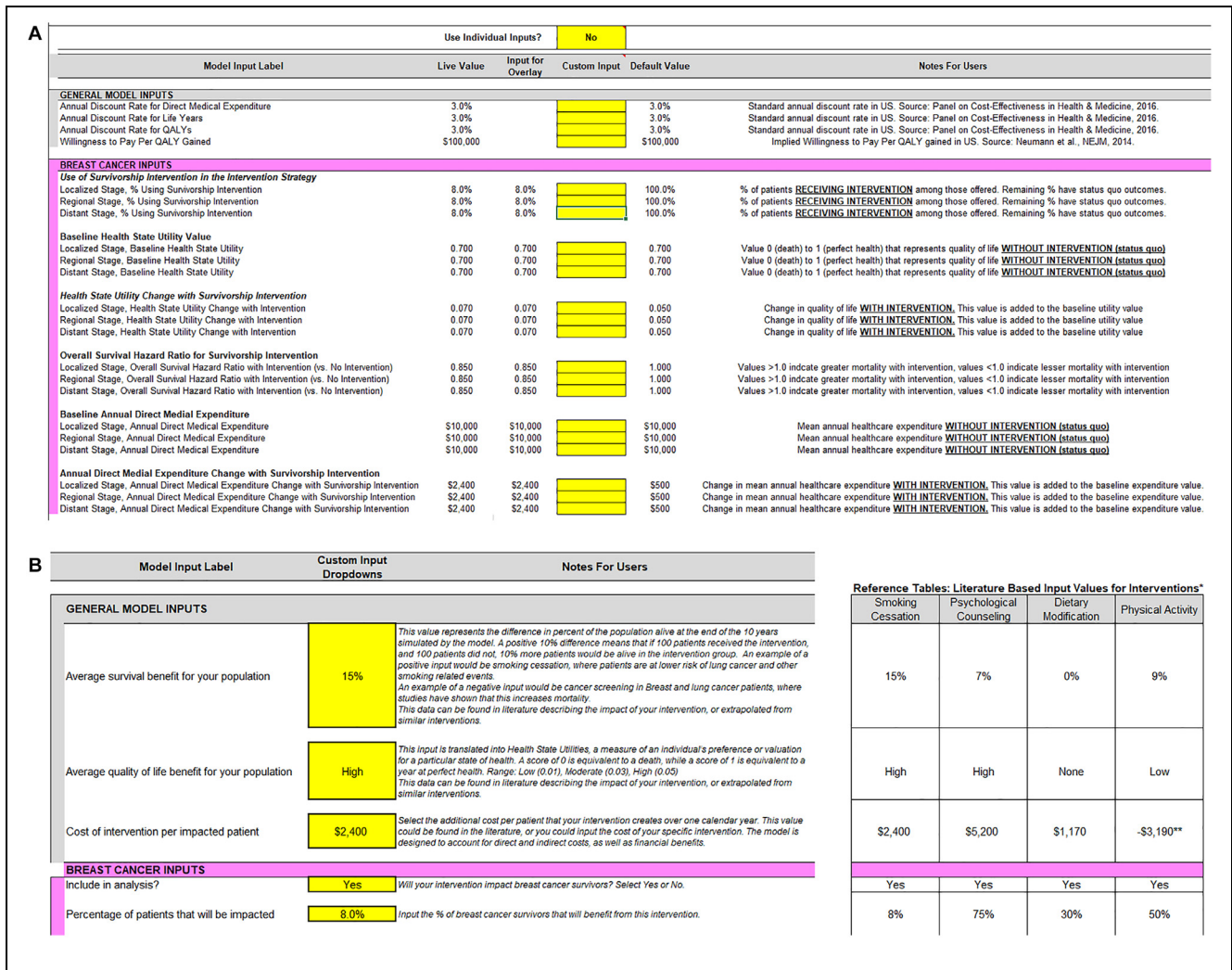


Figure 2 Initial and revised user input. (A) initial: advanced user input – breast cancer and (B) revised: standard user input – breast cancer. This figure shows the user interface for only 1 of the cancer types for easier viewing. As noted in the article, the model contains separate input interfaces for each of the listed cancers.

Results

Participant Characteristics

Group 1 participants were split into 2 different sessions, with the first session including 7 state-level participants, representative of 5 states (Indiana, Kansas, Michigan, South Dakota, and Washington). E-mail feedback was received from 7 individuals and 4 states. The second, follow-up session included 5 individuals from 3 states. States represented in the second session included Indiana, Kansas, and Michigan. Some states were lost to follow-up due to time constraints, changes in roles, and changes in availability. Participants were in many cases

the state comprehensive cancer control (CCC) program’s director, program manager, or equivalent position. These individuals had a background in public health, program management, coordination, and evaluating or making decisions about cancer survivorship interventions.

Participant Feedback

Group 1 participants were interested in the information this decision-making tool could provide to inform programs but felt this version was too technical and complex. Because of its complexity, state-level cancer control planners were uncertain of the benefits of using this

model and did not feel comfortable using the model without assistance from someone with a background in health economics or epidemiology. Group 1 users had no economics background, and the language used was above general health literacy. Plain language for the model inputs and outputs throughout the model was encouraged. These users expressed interest in selecting individual cancer types, as funding agencies may be targeting survivors of specific disease types, rather than all cancer survivors. Overall, group 1 users expressed interest in using a pared-down and more accessible version of the model. Due to the limited funding for survivorship programs, the participants noted that this tool could help programs be more effective in reaching more survivors in their respective jurisdictions. Table 3 illustrates how changes were made with respect to specific feedback.

To address the feedback received, the model was revised. The revisions included creating a new user interface with 2 user input sections, 1 for the typical use case and 1 for users with advanced health economics training.

The advanced user input section, seen in Figure 2, retained all functionality of the original model input page. The typical user section, shown in Figure 2, was created to reduce the complexity and depth of data knowledge required to operate the model. This input page integrated range-limited drop-down menus, rather than free-form input, with restrictions based on effect sizes seen in the literature. The ability to turn each cancer type on and off was added to allow users to focus on specific cancers. Each cancer type was split out into individual results pages. For ease of viewing, only 1 cancer site is shown in the figures presented in this article. Results were updated to return the total net monetary benefit and QALY gain for each cancer type, aggregating the impact of the intervention across local, regional, and distant stage to reduce granularity, as requested by the CCC program participants.

The main difference between the standard (typical) user versus advanced user interface is the ability to examine outcomes by cancer stage. The typical user interface

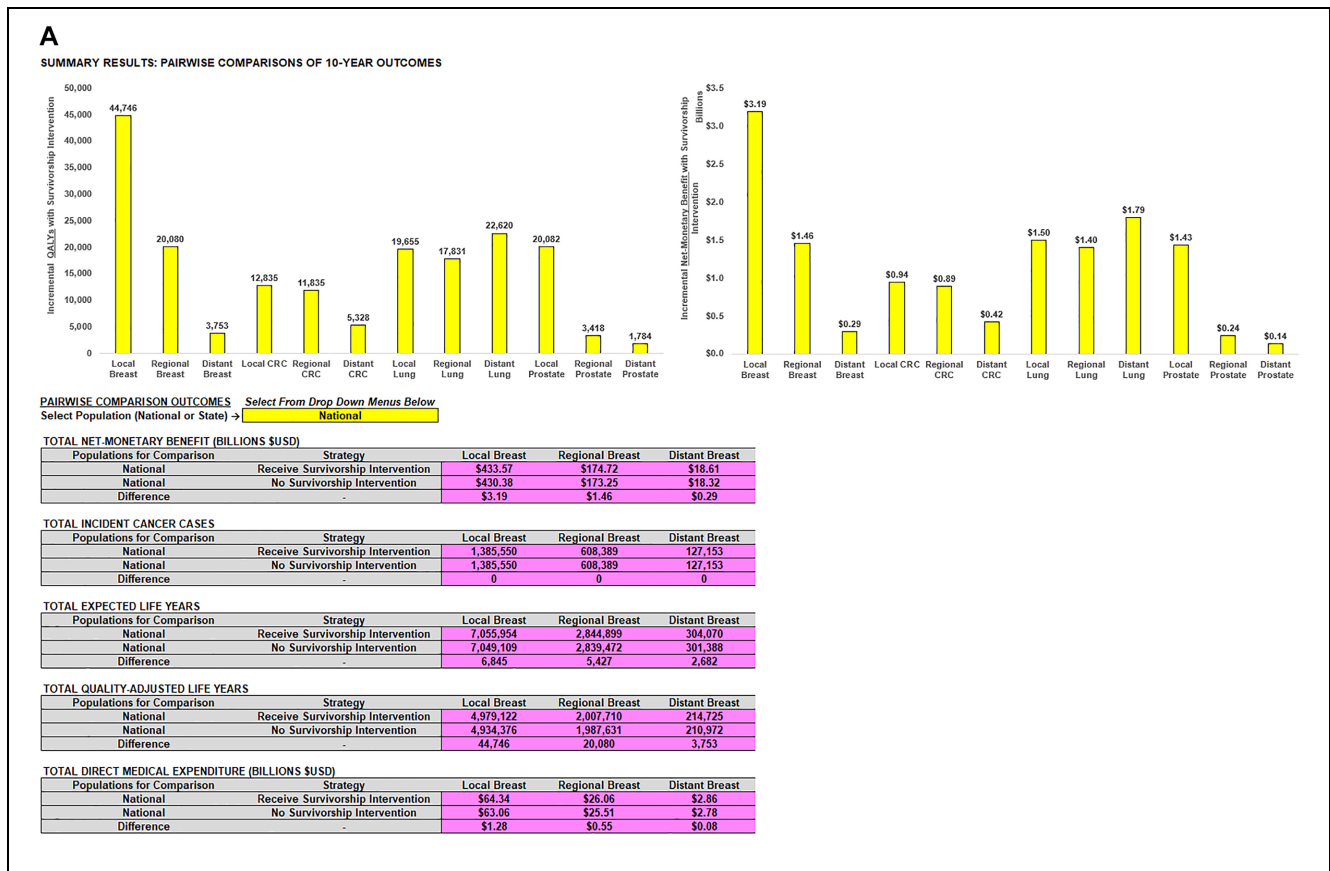


Figure 3 (continued)

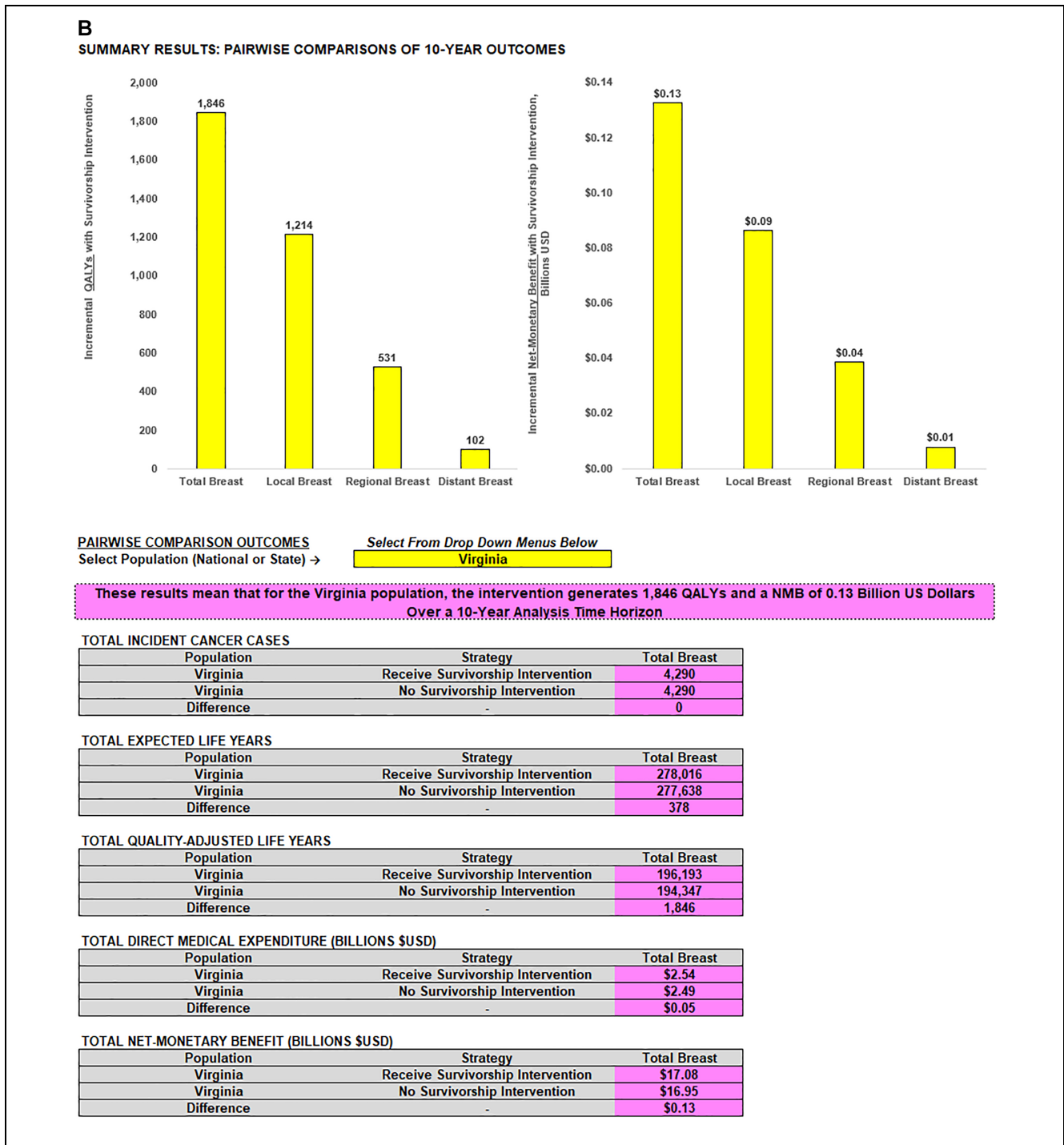


Figure 3 Initial and revised model output. (A) initial: advanced user output – breast cancer and (B) revised: standard user output – breast cancer. This figure shows the user interface for only 1 of the cancer types for easier viewing. As noted in the article, the model contains separate input interfaces for each of the listed cancers.

Table 1 Premeeting Focus Group Questions

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1. What type of survivorship interventions do you implement for cancer survivors?
 2. What are your goals and constraints when thinking about survivorship interventions? How do you prioritize given these constraints and goals?
 3. What other factors are you thinking about when making these decisions?
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Table 2 Postmeeting Questions

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- I. Model usefulness
 - What were your overall impressions?
 - What would make the model more useful to you in your work?
 - What was confusing?
 - What would you like to see in the model that isn't currently included?
 - II. Accessibility
 - What is the extent of your familiarity with the terms used?
 - Did the language resonate with you?
 - How user-friendly is the Excel format?
 - What software or programs are you familiar with for modeling and decision analysis?
 - III. Time frame
 - What is the time frame in which you make decisions?
 - Are you making cases for 10-y interventions?
 - Model currently projects 10 y. What time frame of results would be useful to you?
 - How would you use this model to make decisions about budgets and resource allocations?
-

was designed based on feedback from high-level and mid-level decision makers/cancer control planners who were comfortable and preferred outcomes by cancer type overall. Since most interventions generally broadly target

all cancer survivors, overall outcomes were most palatable and most appropriate for decision making. However, cancer stage-specific information was retained for the advanced user interface for situations in which interventions are needed for these subpopulations.

After participants had dedicated time to test the first revision of the model, they expressed that the modifications, specifically the Standard User versus Advanced User sheets, made the model easier to use overall and less intimidating to navigate. They had a better understanding on how to use and apply the model as a result of the newly incorporated guidance text. The group stated that the usefulness of the tool could come down to the clarity of the instructions in the model and the accompanying user guide.

Feedback from group 2, the CDC reviewers, focused on accessible language and support within the model. Results were simplified to include a sentence that described what the findings meant for the population receiving the intervention ("These results mean that for the [Insert State] population, this intervention generates [X] QALYs and a net monetary benefit of [Y] billion U.S. dollars"). The introduction page was updated to integrate information from the user guide, including the benefits of using the model and explaining how to interpret the outcomes generated. The standard user input sheet was updated to include a reference input table from the user guide, as well as clearer language around the summary ranges for each required input value and definitions of the input values.

Discussion

We adapted a population-level economic simulation model into a decision aid using an iterative, end-user focused model development approach. This process

Table 3 Key Feedback and Updates

Focus Group Feedback	How the Model Was Modified
Initial model interface is overly complex	Addition of standard user input page
Interest in selecting individual disease states, as funding agencies may be targeting survivors of specific disease types, rather than all cancer survivors	Allow inputs for selected disease states and created separate output pages for each disease state
Make language in the model and user guide more accessible	Reworded model file, added definitions to introduction and input pages
Most users will not open an attached user guide for instructions due to technology limitations	Added instructions to model pages, as well as interpretations on result pages
Confusion about sourcing and magnitude of model inputs	Added reference table and input ranges to standard user input page

represents an intersection of the decision making and product development research spaces. Our article contributes to the literature in 2 important ways. First, to our knowledge, we have developed a novel cost-effectiveness model that takes into account national, population-based cancer registry data of US cancer survivors and follows a dynamic cohort over a 10-y time period, enabling the ability to compare various cancer survivorship interventions using economic outcomes of life-years and net monetary benefit. Second, we additionally describe how we modified an economic analysis to translate it into a decision aid for public health practitioners and cancer control planners. While it is likely that informal user feedback has been used to refine cost-effectiveness models in the past, we believe this is the first article reporting how feedback was solicited and integrated into model development.

Using cost-effectiveness analysis to inform medical decision making in the United States has been challenging. There are concerns regarding equity and equality as well as the ethics of reducing a human life to a dollar amount.¹⁰ There are also challenges related to the quality of the model, quality of the data, and assumptions made around input parameters that reflect uncertainty. These can lead to technical challenges and result in nuanced and complex models that can be hard to interpret, further limiting their utility to end users. The primary challenge we describe here is accessibility: getting the model to a state where persons who are trained in public health but not modeling and cost-effectiveness analysis can interact with a model in a way that allows thoughtful input of data and ease of interpretation of the results.

Integrating potential end users (in our case, cancer control planners) into the model design and revision process highlighted themes to consider when developing future user-focused models with the goal of increasing user uptake. The first theme was interface complexity. The original model was visually “complex” with multiple input fields for each value for each disease stage and used health economic terminology, which was viewed as an additional complication. Although this level of detail is important from a scientific modeling standpoint, there can be challenges to adoption, implementation, and long-term sustainment of use. By adding a second input page with fewer fields and better explanations of possible input values, we were able to reduce complexity for cancer control planners while retaining the original input page for users who were comfortable with or needed the increased granularity.

The second theme we identified was ease of use. In the original form of this model, there was a multipaged

technical report and user guide that contained the example interventions, their data, and explanations for how to locate and input data for other interventions of interest. This report also contained information about the purpose of the model and how to interpret the results and integrate them into survivorship program design. Focus group participants identified that storing this information in a separate location from the model, requiring the users to either print a hard copy or toggle between the model and user guide on their screen, would serve as a significant barrier to use. When the information that focus group participants identified as necessary for model use was added directly into the model, they felt it improved the ease of use.

The third theme identified was conceptual complexity. QALYs and net monetary benefit, outcomes in our model, were identified as confusing terms by nearly all participants, as was the use of health state utility values as an input. These terms are commonly used by researchers in the health technology assessment space. However, given the breadth of information that cancer control planners are expected to integrate into practice, these terms may be perceived as technical jargon and become a barrier to adoption. By providing clear definitions of the terms embedded within the model, as well as example ranges for the values needed as inputs (identified from published literature), we were able to reduce the conceptual complexity of the original model. The addition of an in-model interpretation guide increased understanding of results, reducing the complexity around using the model output to inform decision making.

The themes of interface and conceptual complexity, as well as ease of use, create a distinction between cost-effectiveness models designed to answer a research question and models designed to be used in daily practice by decision makers. Research-focused models can contain significant complexity, documentation, and knowledge requirements, as it is likely that they will be used mainly by the developers to answer a specific question. Models that are intended as decision aids and designed to consider additional interventions beyond those used to develop the model may benefit from consultation with the end users. This consultation can focus on reducing complexity in model design and terminology, designing an interface and output that align with the user’s goals, and embedding necessary information within the model itself, rather than in a supplementary user guide. Challenges associated with terminology may be addressed by working with the end users to create agreed-upon definitions for complex terms and concepts that they feel would be easily understood by their peers.

There were limitations to this work; one of the most notable was the process used to construct the focus groups. While it is possible that the 5 states represented in our focus groups fully represent the opinions and goals of other US cancer control programs, there is the potential that other users will encounter additional challenges or barriers that were not identified. In addition, these participants may be those who are most engaged and interested in using this modeling approach to select interventions, and other potential participants may not feel they have the capacity or knowledge necessary to use the model.

An additional limitation is the lack of real-world follow-up for feedback on model comfort and use. In both focus group sessions, participants (who were largely selected for their “leadership” role) identified that they had been able to afford little time to explore the model, given competing priorities around public health needs. As the model design team was present for the focus group discussions and provided walkthroughs during the meetings, users may have only identified complexities in the scenarios presented by the facilitators and not identified other complexities that would occur with routine real-world use. Our ability to conduct user-centered research may have also been hampered by the use of e-mail and video focus groups rather than in-person sessions at local and national meetings or from a series of in-depth interviews with each program where multiple participants could participate.

Future modeling work for public health decision support may integrate this iterative and multipartner engagement approach throughout the model development process. Public health decision makers are faced with complex decisions regarding the allocation of limited resources and drawing comparisons between evidence-based programming. Soliciting feedback from potential end users throughout the model design and refinement process allows the model to more accurately reflect their needs. This approach may also allow a better representation of the real-world challenges associated with the decision being modeled, improving the face validity of the scientific model.

Conclusion




This project provides a perspective on using focus group methodology to refine and disseminate a cost-effectiveness model to assist in selecting public health interventions. We view this approach as an opportunity to remove barriers for evidence-based program selections in public

health interventions and as a step forward in translating cost-effectiveness modeling into real-world use.

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Supplemental Material

Supplementary material for this article is available on the *MDM Policy & Practice* Web site at <https://journals.sagepub.com/home/mpp>.

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