# Using e-Delphi to Evaluate the Pennsylvania Cancer Atlas

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**Abstract**

The Pennsylvania Cancer Atlas (PA-CA) is an interactive online atlas intended to help policy-makers, program managers, and epidemiologists with their tasks related to cancer prevention and control. The PA-CA is designed to support exploratory analysis and decision-making with spatio-temporal cancer data. To assess the usability of the initial versions of the PA-CA, we have solicited user feedback through multiple distributed focus groups and surveys. The process of acquiring user feedback leveraged our e-Delphi tool, which is an online web application designed to support structured input from and sharing of ideas among users distributed in space and time. In this paper we report our e-Delphi method and the results of our investigation with three sets of users. Participants suggested improving interaction functions, enhancing methods of temporal analysis, addressing data issues, and providing additional data displays and help functions. We have found that our extended e-Delphi method has several advantages, including its ease of use, ability to gather information from users distributed in time and space, and the relative anonymity of the participants (allowing people to be open about their comments). Some disadvantages include the need for regular prompting by the moderator, occasional non-participation, and brevity of comments.

**1. Introduction and Motivation**

The paper has two goals. First, it introduces a new, web-based cancer atlas designed to support state-level comprehensive cancer control activities. Second, it introduces a novel strategy for obtaining individual and collaborative input from distributed individuals as part of a user-centered design process. Each is discussed below briefly.

Health atlases represent an important analytical approach for understanding the geographic patterns of disease. By presenting the spatial and temporal aspects of health, they support exploratory analysis, hypothesis generation, and decision-making. In the past, maps of health statistics have offered etiological evidence that led to the identification of explicit disease risk factors. More recently, atlases have also focused upon etiology and prevention of cancer (Blot et al. 1978; Devesa et al. 1999; Winn et al. 1981). Cancer is the second leading cause of death in the United States, with approximately 30% of cancer deaths associated with risk factors that are modifiable (Danaei et al. 2005). Significant variation in the reducible burden of cancer exists by geographic location. This has led epidemiologists, geographers, and statisticians to use maps and spatial analysis methods to seek to reduce the disease burden in specific locations. Initial tools for this work have included Geographic Information Systems (GIS) and atlases.

Despite the fact that GIS and atlases have provided some initial success, best practice methods to analyze and interpret the geographic variations in cancer data have not been developed. Best practice methods could assist policy-makers, program directors and epidemiologists as they implement Comprehensive Cancer Control, a coordinated public health response to reduce cancer risk, improve cancer detection and treatments, and increase access to health and social services.

Today, many health atlases are published online, presenting an opportunity for designers to make them interactive, animated, extensible and linked to other data display methods. In this paper we introduce the Pennsylvania Cancer Atlas (PA-CA), a model atlas designed as a reference to support cancer control efforts. Developed as part of a grant funded by the Association of American Medical Colleges, in collaboration with the Centers for Disease Control and Prevention, the PA-CA makes available interactive maps of colorectal and prostate cancer

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incidence by county. Users of this Atlas will be able to quickly explore relevant data as they plan, implement and evaluate cancer control initiatives.

The PA-CA was developed using a systematic, user-centered design process in which input from a range of individuals was solicited throughout the stages of design, implementation, and system refinement. A key part of our user-centered design methodology involved use of our e-Delphi application for supporting distributed input and discussions. Here, we used these tools in new ways to support both individual response to specific use and usability questions as well as to support distributed, anonymous, asynchronous focus group discussion.

In the first section below, we present an overview of the PA-CA, the background and principles on which it is constructed, and the details of its different components and interactions. We then present our methodology utilizing the e-Delphi application to support the user centered design process we employ to improve the Atlas. Next, we report the results of three of the case studies we carried out with graduate students, experts of cartography and information visualization, and project Advisory Committee. We follow that with a discussion on how the user studies have effected the development of the Atlas and suggested changes, and we conclude with a discussion on e-Delphi as a method for user feedback.

## 2. The Pennsylvania Cancer Atlas (PA-CA)

The Pennsylvania Cancer Atlas (http://www.geovista.psu.edu/grants/CDC/) is a model web atlas designed to present current and timely cancer data to inform health care research and policy. The PA-CA can interactively request and access incidence data based on user choices from a central POSTGIS server (Santilli et al. 2006); these data are projected into maps and other data representations using a Macromedia Flash client (Figure 1).

Cognitive research on the use of health atlases has shown that typical atlas users want to be able to read rates from the maps, recognize regional patterns or clusters in the data, and compare patterns between populations by age, sex and race (Pickle et al. 1999). This has contributed to the evolution of printed health atlases from single maps for each disease to the combinations of maps and graphs for each disease, permitting greater exploration of the underlying data. Building on the design of print atlases, the PA-CA enables users to easily create and inspect multiple maps for effective comparison and pattern recognition. It also provides additional data displays to show specific information about the mapped rates. That the PA-CA is online and interactive further extends the design and function of health atlases by making it more accessible to users and flexible to their interests.

The PA-CA is currently capable of mapping colorectal and prostate cancer incidence on a dynamic choropleth map depicting 67 counties of Pennsylvania. Users can choose the gender, race and age of the population, the site and stage of the cancer, and the time period to be mapped. Users also have the choice of quantile or equal interval classification methods with between two and five classes. Recently, we have incorporated a temporal animation feature to animate the maps through three-year rolling averages of the incidence rates from 1994 through 2002.

A dynamic cumulative frequency plot appears to the right of the map. When the user points the cursor at any of the dots on the plot, the represented county's value and overall rank are displayed, as is an indication of the number of counties that lie above or below the particular value highlighted. The plot is linked to the map, resulting in highlighting in the complementary view. There is also a line in the frequency plot indicating the Pennsylvania statewide incidence rate, as well as stating its total count of cases. The legend for the map is included at the bottom of

the frequency plot.  It indicates the classification breaks, and includes a modified histogram showing the number of counties that fall into each class as well as a box plot.
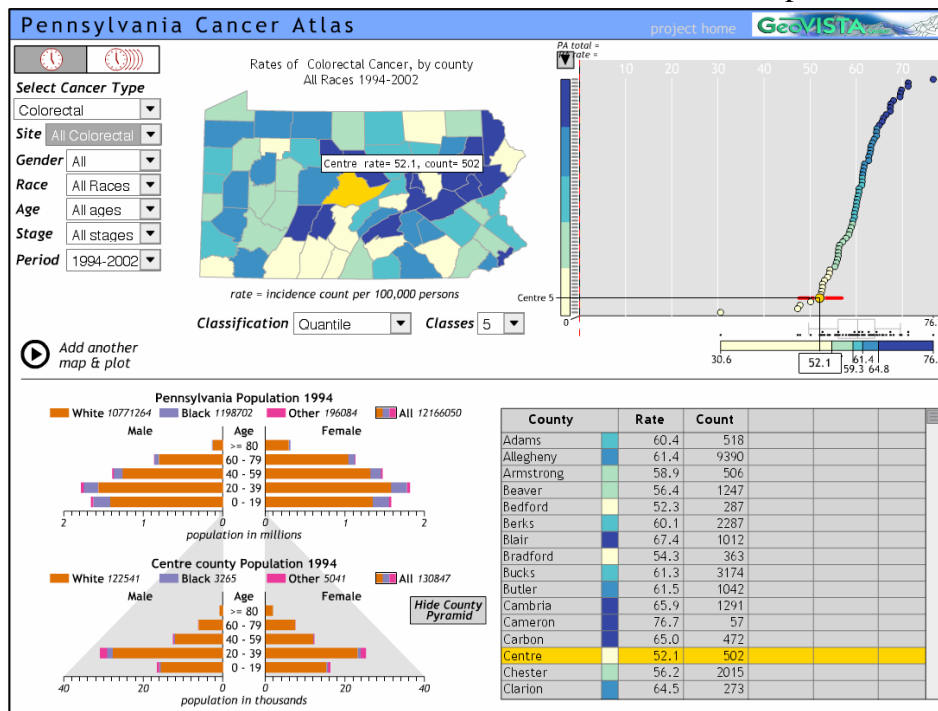


*Figure 1: The Pennsylvania Cancer Atlas, viewable on the web at*
[http://www.geovista.psu.edu/grants/CDC/](http://www.geovista.psu.edu/grants/CDC/)

The lower left corner of the PA-CA interface displays a population pyramid of Pennsylvania (Figure 1) with horizontal bars representing males or females in 20 year age intervals. Different colors in the bars represent white, black and "other" populations. The year of the population represented in the pyramid is linked with the year displayed in the map (or the middle year of the 3-year rolling average).  At the top of the pyramid is a color legend for the races represented with population totals for each.  Selecting one of these boxes will cause the pyramid to display that race.  When a user clicks on a county in the map, a second population pyramid for the county appears below the state pyramid.  Like the state pyramid the county pyramid shows divisions for age, sex and race.  The gray shadow around the county pyramid indicates the number of people from the full state population who are in that county (in the figure, this number for Centre county is a very small proportion of the total).

The table in the lower right corner of the interface lists all of the counties in Pennsylvania with their associated incidence counts and rates.  Each county has a color swatch coupled with it that corresponds to the classes displayed in the map.  It also has some blank columns that are place-holders for additional variables we anticipate adding to a later edition of the atlas.

Two other important features of this Atlas include the interactive linked-brushing between the four data displays, and the ability to view two maps and frequency plots at the same time. The components and features presented in this Atlas are designed to promote an understanding of the geographic variability of cancer.  The interactivity between the map and other components supports this understanding by providing a way to quickly explore connections between the geographic and statistical attributes of the Pennsylvania cancer data. Viewing two maps and plots at the same time also permits easy comparisons between populations.

## 3. User Study Methodology

As noted above, the present study is part of an iterative user centered design process. Iterative user centered design has been used in GIScience (Haklay and Tobon 2003; Robinson et al. 2005; Slocum et al. 2003) to improve the usability of software tools so that they can be better suited to the tasks of the end user. Robinson et al. (2005) proposed one method of conceptualizing the user centered design process (Figure 2).
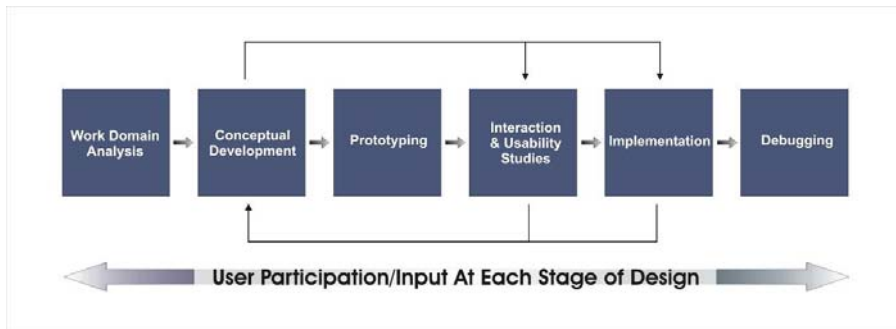
*Figure 2: The user centered design process (after Robinson, 2005)*

In this paper we adopt a similar approach to incorporate user feed back in each stage of the PA-CA development. To evaluate the PA-CA we have chosen to utilize multiple opinion and knowledge elicitation techniques, including focus groups and surveys (open and close ended). As mentioned previously, we have adapted the GeoVISTA Center's online e-Delphi web application to conduct our focus groups and surveys with several different expert and/or user groups.
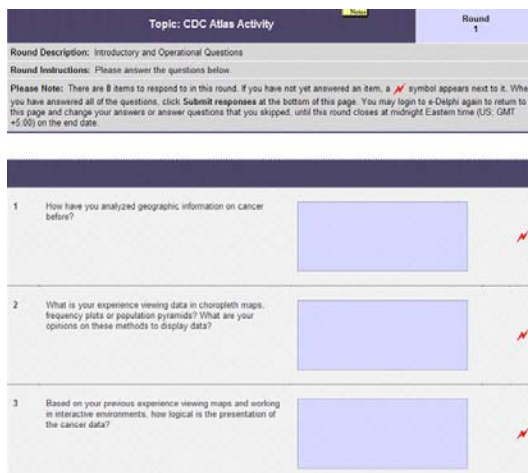
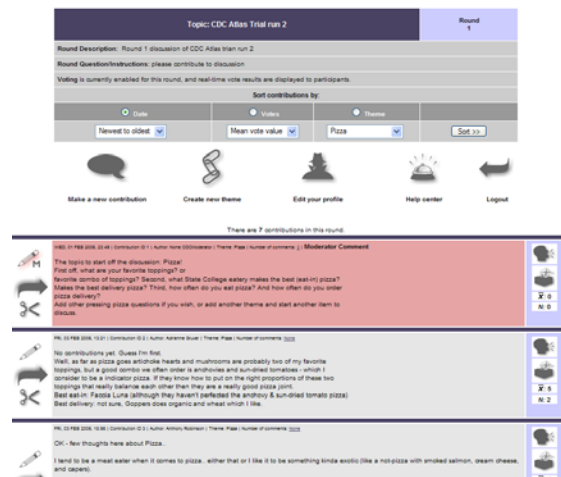*Figure 3a: The eDelphi tool for web discussions: Survey style questions*

*Figure 3b: Discussion style (Moderator vs. Participants) in eDelphi*

### 3.1 The Delphi Method and e-Delphi Application

E-Delphi is a web application designed to facilitate distributed Delphi exercises. The Delphi method was created shortly after World War II by the RAND Corporation as a way for structuring group decisions in a way that ensures individual personalities and social relationships do not impact the ideas that are presented (Dalkey 1969). The Delphi method operates by having

participants work iteratively through ideas in a distributed, anonymous manner guided by a moderator. Moderators receive feedback on prompts from each participant, and then distill this feedback to develop ideas for subsequent discussion rounds. e-Delphi (Pike et al. 2005) adapts the Delphi method for use via the internet. Exercises occur in a web portal where moderators can create and conduct rounds of Delphi discussion. We have chosen to use and extend e-Delphi to conduct distributed and anonymous software evaluations. Evaluation activities often require significant investments of resources to organize activities and to procure technology to capture user responses. e-Delphi provides us with the ability to conduct formative evaluations via the web with very little tangible cost. The types of activities that e-Delphi currently supports include: surveys, metrics, free responses, voting, and threaded discussions (Figure 3a and Figure 3b). Rounds and activities can be set up depending on the kind of feedback that the moderators are looking for. In the current study a modified version of the Delphi method is used. We are using the e-Delphi application to support a modification of the focus group method that shares with Delphi anonymity and that shares with e-Dephi the ability to have distributed groups.
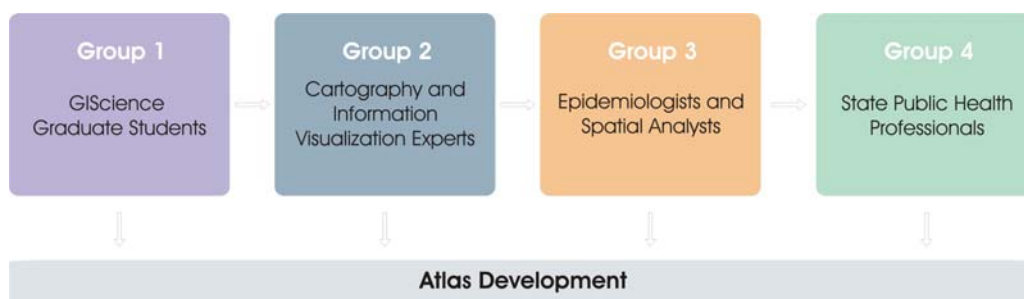


*Figure 4: Case Studies to evaluate the Atlas Development Process*

The present study has four sets of focus groups (Figure 4) with different groups of experts as part of the iterative design. Results from each step will inform the design of the Atlas to help improve its utility and usability. The participant groups include two sub-categories: (a) groups one and two represent individuals with expertise in geospatial information representation and analysis and/or in information visualization more generally; (b) groups two and three have expertise in the domain to which the Atlas is targeted (comprehensive cancer control). Our decision to use four different groups of evaluators is based on our assumption that each group will have different things to offer in terms of critiquing the atlas and suggesting improvements. Expert evaluation is a common usability technique (Nielsen 1993), and users from the first three groups (graduate students, cartographic/visualization experts, and the atlas advisory council) can be considered experts from relevant domains. Because e-Delphi allows us to quickly re-shape evaluation activities and conduct them via the web, we opted to solicit feedback from a wider audience than we may have chosen had we been constrained by more typical usability methods.

In the present set of user studies, we have used a combination of survey and discussion styles to facilitate different kinds of input from the different sets participants. Through this strategy we have also begun to understand the strengths and weaknesses of the e-Delphi tool as a method of conducting web-based user evaluations. The following sections describe in detail the results for each of the three case studies we have completed. The initial case study is reported in a sequential manner to help the reader understand the overall process. Subsequent case study results focus on key themes to avoid unnecessary repetition.

**4.1 User Group #1 – Grad Students from an Advanced GIScience class.**

The first round of our e-Delphi evaluations for the PA-CA was conducted with a group of seven graduate students who participate in GIScience research at the Penn State GeoVISTA Center. These students have a wide range of specific GIScience interests, and in general they are experienced in the application and design of GISystems, mapping, and related technologies.

We asked this user group to complete two rounds of short answer questions and one short survey. The first round of questions focused on evaluating prior experience with similar techniques and opinions on the basic interface/interaction design of the Atlas. The second round shifted attention to the scenarios in which the PA-CA may be useful. The survey asked users to rate the PA-CA according to a set of basic usability criteria.

Two students responded that they had prior experience working with geographic data on cancer. All of them had prior experience using choropleth maps and had at least seen or heard of frequency plots and population pyramids. Opinions regarding the suitability of these methods for an online atlas were positive – most users felt they would be interpreted easily by non-experts. Some mentioned that the frequency plot may be confused with a more traditional scatterplot.

Reactions to the layout and presentation of each tool in the PA-CA were also positive. The simplicity in form and function of the PA-CA was appreciated, and it was judged to be similar to a paper atlas in terms of presenting organized and useful information. The primary weakness that users mentioned was the lack of tooltips and other help features to explain classification methods and related features that are not self-explanatory to novices.

In terms of interactivity, users had positive things to say about the linked-brushing feature, claiming that it aided quick interpretation by connecting data across views. Users had trouble changing the population pyramid between county and state views, due to a bug we had not discovered previously. Others suggested a tool that would allow them to view additional metadata, such as county names and axes labels.

When asked to suggest additional functions and features for the PA-CA, users provided a long list of potential development goals. The most common request was to allow the selection of multiple counties to make comparisons between groups of places. Users suggested we follow common interface conventions to do this, by using bounding boxes and/or shift-clicking. Others suggested changeable aggregation units to zipcode areas, tracts, and congressional districts. Two users specifically requested the ability to change map class breaks and color schemes.

The PA-CA version we tested with this group of users had a blank quadrant in the lower-right of the display. At the time we had not made a decision regarding what information to provide there, so we asked this group to think about potential solutions. The general consensus was that this space should be used to provide metadata to describe in how rates are gathered and what they mean. This could also include information about each cancer type, who it impacts, and treatment methods. Some suggested that this space would be a good place for help files.

The potential applications that users saw for the PA-CA were primarily related to public health analysis and decision making. A few felt that it may be a good example to use when teaching map literacy and cartographic design. Users described scenarios in which analysts might use the PA-CA to identify areas where health education and screening efforts could be targeted, or to monitor the effects of existing campaigns over time. Because the PA-CA was seen as generally easy to use, decision makers may use the PA-CA to evaluate claims about particular risk factors (perhaps environmental or social) in certain areas and to create graphical reports for dissemination. This need to support output of displays in a form that enables integration in

reports echoes ideas that our advisory committee had offered earlier. As a step in this direction, we have implemented PDF output which saves displays in an editable vector format.

Responses to our brief usability survey, one we developed based on the System Usability Scale method (Brooke 1996), were positive across the board. Users indicated that the PA-CA was easy to use, provided well-integrated tools, and that people would be able to learn how to use it quickly. The only question on which opinions were mixed was whether or not users would need detailed help/tutorials in order to use the atlas. Half agreed and half disagreed on this point.

**4.2 User Group #2 – Information Visualization Experts and Cartographers**

The second round of our e-Delphi evaluations was conducted with a group of four users – two information visualization experts (both active researchers with some work on map-based visualization environments and on usability) and two research cartographers who have been active in the areas of cartography and GIScience for a number of years and who also have conducted usability studies. This second user group was asked to complete two rounds – one discussion round followed by a survey round.

Three prompts were chosen to begin the discussion; they focused on: (1) The data display methods used in the Atlas; (2) The interactivity between the various information displays, and (3) The aesthetic design and usability of the interface. Following the iterative, asynchronous discussion we used a few open-ended questions generated from the discussion to follow up on a subset of issues that seemed to have importance in the development of the PA-CA. This we followed with a few survey style questions to understand the overall reaction of this user group to the Atlas. The survey style answers suggested that the Atlas was easy to use for this group. Participants agreed that it provided an interesting and novel approach to exploring health data and the links between the interfaces were especially useful for this purpose. There was also a general consensus was that there were no functionality or usability issues that were critical, although two participants could not decide whether aesthetically the Atlas followed common cartographic design principles. All agreed that providing detailed tutorials would be useful. The open ended questions and the discussion have given a number of additional issues which we discuss in detail below, grouped by theme.

*4.2.1 Usability and Functionality:* Several suggestions were made about improving the user interface in two basic categories - design and interactivity. In terms of design issues there were several consistency issues that needed to be addressed regarding sizes and styles of fonts, labels and scrollbars. One suggestion was to change the mouseover action to display the label transparently in order to see the map below. Multiple participants suggested that the frequency plot needed labels for the axes. In terms of placement, position and size, users suggested shifting the map legend underneath the map frame to aid clarity. Suggestions also focused on increasing the size of the map and making each element of the Atlas hierarchical in terms of size to emphasize their relative importance. Users also recommended that the population pyramid remain visible when the second map was displayed. In terms of interactivity, the interaction between the population pyramid and the map was not very intuitive to most of the participants. Finally, participants suggested that it might be difficult for non cartography-information visualization experts to understand the interface intuitively. To address this, they suggested incorporating a help system into the PA-CA.

*4.2.2 Temporal Analysis*: The lack of a temporal component to the Atlas, except when two maps are displayed together of different time periods, generated some discussion. Suggestions were made to incorporate a temporal analysis component. One suggestion was to provide either a trend analysis plot or use animation with a time slider bar for user interaction. Alternately, both methods may be useful to provide more options for users.

*4.2.3 List/table/exporting data:* Most of the participants in this group indicated the need to supplement the interface with a list, table, or similar view of the raw data. One suggestion was to provide a basic table from which users could copy values into spreadsheet software. Following up on these suggestions we prompted some more discussion on how data can be captured or exported from such an interface. Screen captures, PDF, and PowerPoint exports were some of the suggestions. One participant suggested a tool for *importing* data. As a result of these suggestions the Atlas was updated with an animation tool and a scrollable, linked table.

## 4.3 User Group #3 – Epidemiologists and Health Researchers

The third round of our e-Delphi evaluations was conducted with a group of six users. This group includes epidemiologists, health researchers and spatial analysts who are part of the advisory committee for the Atlas. This group is familiar with the motivation behind the design of the Atlas. Group members have experience researching and generating policy pertaining to public health. Most are familiar with spatial analysis and/or mapping of health data.

Similar to the previous focus group, this group participated in two rounds. To be sure that we captured participants' opinions on several specific questions before they began to discuss issues across the group (where they are likely to influence each other), we began with a survey round and ended with a discussion round. The survey round had eight questions and after the round was over, a summary of the answers were made available for the next round of discussions. Initially, they were asked to comment on the summary statements for each question. They were also asked to check in later and comment on other people's contributions. Therefore, the second round had a discussion of the main issues as well as some threaded discussion.

It is important to mention that before the third focus group started, the Atlas was updated with a temporal animation feature and a scrollable table. The population pyramid was also updated with an additional county level detail pyramid below the state-level pyramid.

We began the survey with questions about the kinds of people that would be likely users of the Atlas and the kinds of analysis the Atlas could support. The general consensus was that the Atlas would be useful for making spatial comparisons, retrieving cancer data, and making decisions based on the location and incidence of cancer at the county level. It was perceived primarily as an exploratory tool rather than a hypothesis testing or modeling tool. Participants envisioned users of the Atlas to include educators, planners, state/county health department staff and cancer registry staff. One participant thought that the Atlas could also be used for general cancer data exploration and hypothesis generation as well. The general perception was that it is too general for high level analysis and a little too complicated for general public use. Additionally, survey results provided feedback as discussed below under three specific themes.

*4.3.1 Usability and Functionality:* There were several suggestions for improving the usability of the Atlas. The first set of these focused on links between the features. All the respondents found the links between the different plots and maps were very useful. However it was also clear that participants had problems understanding the links between the population pyramid and the map.

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The second set of usability suggestions focused on the new table and the animation features that had been recently added to the Atlas. Most participants felt that the table needed to have some additional features. These included: sorting of the table by any column; export of the data in various formats; additional columns for variables such as time trends, incidence rates, standard error, confidence bounds, and rate ratios. The animation feature drew a lot of attention, but was also a source of confusion for some participants. Overall, users were impressed with the feature, but one participant mentioned that the icons were not very intuitive. We assume that he may have missed it initially and found it only when he saw a direct question posed about it. Another user pointed out that the requirement to rewind the animation before re-playing it was counterintuitive. Two suggestions were made for additional components: the ability to select a county and see its change over time and the ability to print summaries of temporal data.

A third set of suggestions focused on the terms used in the Atlas. This did not seem to be a major concern as most people thought that the Atlas terminology would make sense to the target audience. Some minor suggestions focused on a few terms such as "in-situ" and "align x axis". On the whole, users suggested that providing tutorials with explanations of the features and their interactions, especially the slightly complicated features such as the population pyramid and time series animation, would be a good idea.

*4.3.2 Data Issues:* Some participants asked for data types beyond those currently provided in the Atlas. These include data on all types of cancer sites e.g., breast, cervical, lung, ovarian, skin; total cancer burden, all cancers combined and cancer mortality rates. One additional suggestion was to provide the ability for maps to display the output of different kinds of spatial analysis methods, such as Poisson probability estimates and Bayesian smoothing.

Another important concern about the data focused on the rules for adjustments. These included stating the source of the data and the kinds of adjustments made (age, small numbers, single year rates, edge effects due to display of single state data) and detailing data suppression rules that have been/might be used in the Atlas.

*4.3.3 Additional Display /Analysis Methods:* As a next step in development of the Atlas, we envisioned the inclusion of a tabbed window to support more information components than can fit on the screen at once. An objective of our work with group three was to obtain input on this idea. One of the components planned for the tabbed window was the current scrollable table. When asked to suggest additional displays that could be attached to tabs in this window, several suggestions were made. These included scatter plots of populations with incidence rates; individual micro maps or micro maps in combination with other plots; trend maps showing analysis over 10 years; multiple maps showing temporal change instead of the animation; and a data screen having details of underlying statistics, risk maps, information on SES, median income, and data on smoking, health insurance, obesity, and other indicators.

## 5. Discussion of the Results

Goals for our evaluations were to obtain input on the overall usefulness of the Atlas, to identify problems that end users might encounter while using the Atlas, to assess the general difficulty level of the Atlas, and to identify the components that need to be redesigned. Across all three user groups there was positive appreciation for the interactive Atlas. The difficulty level was judged to be low and the Atlas' potential to be used successfully by the end users was judged to be high. Participants were positive about the potential of the Atlas to serve as a model

tool for exploring and analyzing health data. Specifically, the inclusion of linking and brushing across all the different features in an application targeted to a diverse and non-geospatial audience generated considerable enthusiasm.

Several problems were identified related to functionality, usability and data depicted that need to be taken into consideration for the next Atlas update. While minor usability and functionality changes were made between the first and second user study and some major changes and addition of components (the animation feature and scrollable table) were made between the second and third studies, additional minor and major changes need to be considered based on participant input. The next major changes include adding components to the tabbed window and including a tutorial feature. Once these changes are made, we plan to conduct a fourth focus group with public health analysts who comprise our most important end users.

Because the PA-CA design is intended to become a model for the development of other state-level cancer atlases, our work with the Atlas is poised to have a large impact. This goal carries with it a responsibility to ensure that we are carefully considering the end-users of these tools. Therefore, as we continue to improve the design of the PA-CA, we will continue to solicit user feedback. Challenges to the success of the PA-CA as a model include adapting to different data / health priorities, and technical challenges in terms of layout for oddly shaped states.

## 6. E-Delphi as a Method for User Feedback

E-Delphi has allowed us to gather feedback quickly and efficiently from a wide array of experts. We hoped to simulate traditional focus groups and other in-place evaluation methods to solicit similarly rich results. The authors have prior experience conducting tool evaluations, and in practice, it is more difficult to stimulate discussion through e-Delphi than it would be if moderators and users were co-located. In-place, synchronous focus groups and other user evaluations allow moderators to immediately interpret instructions when necessary, while e-Delphi does not provide this kind of feedback mechanism. When users struggled to understand particular questions, they were likely to be providing input at a time when the moderator was not online, so there was no easy way to ask a question before proceeding.

While responses in e-Delphi are not necessarily limited in length or composition, we have found that participants provide less input than what is typically gathered from focus group or interview transcripts. That said, we were almost always rewarded with insightful responses to our questions. Another limitation found while conducting discussions was that the moderators needed to prompt often in order to maintain an inflow of responses.

In general, the feedback we have received through e-Delphi for this evaluation effort and one other (see Weaver et al. Submitted) has been quite valuable to our design and development efforts. E-Delphi may not provide the immediacy or depth of a more traditional in-place evaluation, but it does provide the opportunity to quickly gather feedback from users who are not easily available to us in the same place at the same time. These are advantages that will lead us to return to e-Delphi for future evaluation activities when we are faced with similar constraints on assembling a representative group of expert evaluators or target users in one place at one time.

We are working to extend e-Delphi application to better support evaluation efforts. We plan to design custom interfaces that allow mixed methods within a single session (the current application does not, for example, allow a session to include both open discussion and a structured survey). Additionally, we plan to enhance the suite of moderator tools to support more flexible development and control of sessions. After the completion of all four user studies, we plan to have our participants evaluate e-Delphi as a means of conducting a usability study.

## Acknowledgements

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