International Cartographic Association
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Understanding Users in Small Area Cancer Mapping: Insights from the Early Stages of a User-Centered Design Process

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Abstract: Cancer mapping is critical for understanding the spatial patterns of cancer burden, identifying disparities and informing targeted interventions. However, the limited availability of accessible, local-level cancer data and user-friendly mapping tools hinders both professional users, who need finer-scale data to analyze community-level cancer burden, and the general public, who need clear and intuitive visualizations to better understand their cancer risk. Cancer Analytics and Maps for Small Areas (CAMSA) is a visual analytics platform designed to address the diverse needs of end users, including the general public, public health professionals, and researchers, by visualizing small-area cancer data. This paper presents the early stages of CAMSA's development following an iterative user-centered design (UCD) process. Through needs assessment interviews, usability evaluation focus groups and implementation capacity surveys, we identified five use cases: cancer burden exploration, health disparities identification, risk factor analysis, customized spatial and statistical analysis, and communication and collaboration. The alpha version of CAMSA was developed to fulfill core functional requirements to detect spatial patterns (e.g., clusters) of cancer burden across different stratification groups including race, sex and year. Usability evaluations, conducted through post-development focus groups, informed the extended functional requirements for the beta version to enhance its functionality. Findings from this iterative process underscore the importance of meeting the needs of the general public (providing comprehensible knowledge), and public health professionals and researchers (clarification of statistical uncertainty). This study showcases the effectiveness of user-centered design in ensuring the accessibility and practicality of CAMSA.

Keywords: cancer mapping, user-centered design, cancer prevention and control

1. Introduction

Choropleth maps displaying cancer rate estimates have long been used by public health professionals, researchers and policymakers to analyze the spatial distribution of cancer burden. These maps, featured in resources like State Cancer Profiles (National Cancer Institute, 2024) and Cancer InFocus (Burus et al., 2023) provide valuable insights for cancer control and analysis. However, the absence of sub-county maps remains a significant limitation, especially for community-level investigations and exploration of cancer disparities among small population groups. Specifically, data suppression in areas with small case counts and the lack of statistical stability associated with small population denominators pose challenges for investigating low-incidence cancers or cancer disparities, especially among populations that may have low case counts (e.g., rural populations, racially minoritized groups).

In recent years, sharing health data with the general public has become more common in cancer prevention and control; yet, the challenge of comprehension remains unsolved. For example, there is a recent trend towards

Advances in Cartography and GIScience of the International Cartographic Association, 5, 7, 2025.
32nd International Cartographic Conference (ICC 2025), 17–22 August 2025, Vancouver, Canada. This contribution underwent double-blind peer review based on the full paper. https://doi.org/10.5194/ica-adv-5-7-2025 |

collaboration with patient advocates, who actively interact with researchers, healthcare professionals and policymakers to promote cancer research and inform policy decisions (Anampa-Guzmán et al., 2022). However, cancer rates are usually not exact values but estimates generated using various statistical methods (Richards et al., 2009a), which makes the data difficult to communicate to non-data-trained users (i.e., the general public). Further, the complexity of statistical processes – such as population size normalization, age-adjustment, and uncertainty measurement – adds an additional layer of difficulty in interpretation. To address these challenges, involving end users in the visualization design process is necessary to identify user needs and ensure the end product is comprehensible to the general public, while maintaining the analytical capability required by professional users.

User-centered design (UCD) offers a promising solution for tackling these challenges in interactive mapping by focusing on the needs and perspectives of diverse end users (Roth et al., 2017). Usability evaluation and UCD principles have been successfully applied to the design of cancer mapping tools, such as the Exploratory Spatial-Temporal Analysis Toolkit (Robinson et al., 2005), the Pennsylvania Cancer Atlas (Bhowmick et al., 2008), and the LionVu from Penn State Cancer Initiative (Geyer et al., 2020). However, prior efforts have primarily targeted professionals and researchers as end users, and involvement of the general public remains limited. As the general public's interest in cancer data grows, including this group in the development process is essential for improving the accessibility and usability of cancer mapping tools for broader audiences.

To bridge this gap, this study aimed to design and implement the Cancer Analytics and Maps for Small Areas (CAMSA) platform to meet the needs of multiple user groups, including the general public, public health professionals and researchers, by adopting a UCD approach. This paper presents the early iterative stages of developing the alpha and beta versions of CAMSA. These processes involved collaboration with stakeholders including cancer advocates, nonprofit staff, public health professionals, and epidemiologists from Iowa, Kentucky, and New Mexico to ensure the practicality of the platform.

2. Literature Review: Overview of Recent Cancer Mapping Tools and Techniques

State Cancer Profiles (National Cancer Institute, 2024), developed by National Cancer Institute (NCI) and Centers for Disease Control and Prevention (CDC), has been widely used by health planners, policymakers and cancer information providers since 2003. These static maps display county-level cancer data, including incidence, mortality, risk factors, screening, and demographics. The NCI Cancer Atlas (National Cancer Institute, 2024a) includes similar datasets but presents them in an interactive map offering geographical exploration features such as panning, zooming and multiple map comparison views. The Pennsylvania Cancer Atlas (Bhowmick et al., 2008) combines maps, graphs, and tables for cancer incidence and mortality, while Cancer InFocus (Burus et al., 2023) integrates and updates data from various sources in an interactive platform. These tools primarily serve cancer control planners, public health professionals and researchers, offering data at the county level or higher.

Using county-level data is one way to protect patient privacy and address instability in small population areas. While cancer cases are collected with precise coordinates, they are often aggregated into larger geographic units such as counties, and case counts below 15 are suppressed to prevent identification in sparsely populated areas (Richards et al., 2009b). However, this limits data availability for rare cancers. Furthermore, small populations often produce highly variable estimates, resulting in unreliable data. Advances in small-area statistical methods, like Bayesian hierarchical modeling, enable reliable risk estimates by leveraging neighboring data (Sui, 2007; Ward et al., 2019). Yet, these methods remain underutilized in making small-area estimates accessible to diverse users, including the general public, public health professionals, and researchers without extensive biostatistics expertise.

3. Methods

3.1 Small-Area Cancer Estimates

We generated small-area cancer estimates using Bayesian Conditional Autoregressive Models which borrow strength from neighboring areas of small counts and highlight regional trends (Jay et al., 2021; Ward et al., 2019). These models preserve locale-specific contextual information while smoothing the inherent variability and excess of zeros in the data. These methods also allowed the flexible exploration of risk measures, going beyond just crude and age adjusted rates to showing measures of evidence – risk probabilities. We computed the estimates of age-adjusted rate and risk probability for incidence, late-stage incidence and mortality across eight cancer types: colorectal, female breast, cervical, liver, lung, melanoma, non-Hodgkin lymphoma, and prostate cancers. These estimates are provided at the ZIP code tabulation area (ZCTA) and county levels. Additionally, we computed these estimates for different population and diagnosis year strata, allowing users to investigate differences among population groups and temporal trends.

3.2 User-centered Design Process

We employed a UCD process to design and develop CAMSA, incorporating user feedback to address the analytical needs of professional users for small-area reasoning while ensuring the platform remains accessible and user-friendly for the general public. The early-stage process, shown in Figure 1, included a needs assessment, usability evaluation and implementation studies to establish user requirements for the alpha and beta versions of CAMSA.

3.2.1 *Needs Assessment Study*

We started the UCD process with a needs assessment study

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aiming to conceptualize target users and use case scenarios. First, we met with co-investigators from Iowa, New Mexico and Kentucky to identify potential users relevant to cancer prevention and control. We identified seven potential end users from a wide range of backgrounds and invited them to participate in the pre-development interviews. After these interviews, we transcribed and analyzed the recordings to elucidate key user profiles and use cases. The results led to formalization of the core functional requirements and development of the alpha version.

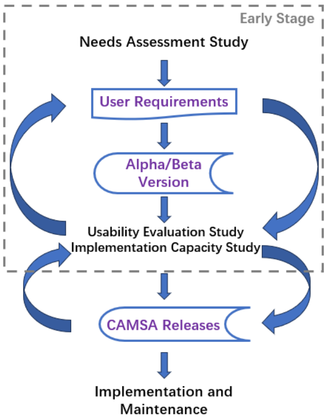

Figure 1. User-Centered Design (UCD) process of developing CAMSA. The processes within the grey dashed-line box represent the early stages described in this paper.

3.2.2 *Usability Evaluation*

The usability evaluation of the alpha version was conducted as a formative assessment to gather insights into how effectively CAMSA met user needs and what extended requirements are needed to support small-area cancer mapping tasks. The purpose of this evaluation was to identify usability issues, understand the reasons behind them, and refine CAMSA's design to better serve both professional users and general public. By focusing on the "why" and "how" of user interactions, the formative evaluation aimed to detect problems early in development and ensure the platform's functionality aligned with the intended use cases. Following the development of the alpha version, the interview participants and additional potential end users were invited to participate in post-development focus groups. Focus groups were held in the form of a group interview with a small number of participants. It is a cost-effective and efficient method to explore user needs and expectations during early development stages by identifying shared issues or divided issues of a user group (Kessler, 2000). These sessions included a demonstration of the alpha version's functionalities, followed by participant feedback on usability and utility. The focus groups allowed us to observe users' interactions with the platform, understand their thought processes, and identify areas of confusion or difficulty. We conducted 7 focus groups with 23 participants via video conferencing. Focus groups were transcribed, and a thematic analysis was conducted to identify usability challenges and features of the tool to improve for the beta version.

3.2.3 *Implementation Capacity*

To understand feasibility of expanding CAMSA beyond our initial implementation areas in Iowa, New Mexico, and Kentucky, we conducted an implementation capacity study using surveys. We conducted surveys with the alpha version during two national meetings, the North American Association for Central Cancer Registries Annual Meeting and the Surveillance, Epidemiology, and End Results Research Meeting. These events routinely attract public health professionals and cancer registry experts who could potentially implement CAMSA in their settings. The survey included questions about how participants would use CAMSA and their capacity to integrate it into their registry workflow. We collected a total of 17 responses and analyzed them using descriptive statistics. These insights provided valuable details on use cases and requirements to support CAMSA's implementation.

4. Results

4.1 End users and Use Cases

We formalized user profiles and use case scenarios based on the results from needs assessment interviews and the implementation capacity survey. Potential end users of CAMSA include:

1. **General public** (e.g., cancer advocates, reporters, cancer survivors and caregivers) who are interested in understanding the cancer burden but may lack professional training in health science or spatial data analysis.
2. **Public health professionals** (e.g., oncology directors or program managers) who are experts in cancer prevention and control but may have limited experience with spatial data science.
3. **Researchers** (e.g., epidemiologists or data analysts) with advanced data analysis skills.

We identified five primary use cases for these users:

1. **Cancer burden exploration**: Identifying cancer rates in specific communities and detecting spatial patterns or clusters of cancer burden.
2. **Health disparity identification**: Assessing disparities in cancer burden and resource accessibility among populations.
3. **Risk factor analysis:** Investigating relationships between cancer rates and associated risk factors.
4. **Customized spatial and statistical analysis:** Exporting data for external spatial or statistical analysis.
5. **Communication and Collaboration:** Sharing knowledge and facilitating collaboration among diverse stakeholders.

We identified that different end users would use CAMSA with different use cases. The general public users were more likely to focus on cancer burden exploration, risk factor analysis, health disparity identification, and communication. They would use the tool to explore the local cancer burden and disseminate knowledge to help residents understand their community's health challenges. Advocates might also collaborate with public health professionals to advocate for interventions aimed at high-burden areas. Public health professionals (e.g., cancer prevention and control program managers) might share similar use cases but with additional responsibilities, such as conducting community health assessments to identify hotspots and guide interventions such as cancer screening and early detection programs. Public health professionals may also use CAMSA to share information with policymakers and facilitate collaboration at the state level. Researchers were most likely to leverage CAMSA for all five identified use cases, particularly for customized analyses. They may use CAMSA to explore spatial patterns and generate hypotheses for their research projects. Additionally, they were more likely to export datasets from CAMSA to conduct statistical analyses, such as investigating ecological associations with cancer risk factors, or comparing CAMSA's modeling methods with tools like SaTScan (National Cancer Institute, 2020). CAMSA may also support researchers in grant writing.

4.2 Core Functional Requirements and Alpha Version

Based on the needs assessment study, we identified core functional requirements of CAMSA, summarized in Table 1, and designed three interface panels for the alpha version to meet these needs:

1. **The Data Configuration Panel (Figure. 2a):** This panel allows users to configure cancer burden estimates with different stratifications. In the Data Configuration Panel, users can select the areal unit, cancer type, estimate measure and stratification options. This panel also supports highlighting high- or low-burden units by ranking or filtering based on age-adjusted rates percentiles, or risk probability thresholds.
2. **The Map Panel (Figure. 2b):** This panel displays estimates on an interactive map, with hover-over functionality to show unit-specific details (e.g., ZCTA ID, city, estimate value). To ensure accessibility for the general public, explanatory notes below the map define key terms (e.g., age-adjusted rates, risk probabilities) and provide examples of interpretation. Table 2 illustrates example notes for colorectal cancer incidence (2014–2018).
3. **The Data Table Panel (Figure. 2c):** This panel complements the map with additional visualizations. When users apply filters to highlight high- or low-burden units, a dynamic table displays filtered results below the map.

Requirements	Solutions
Data Configuration Panel	
Identify cancer burden in specified geographic areas	• Areal Units: ZCTA and County
Compare different cancer types, statistical estimates and cancer stages	• Cancer: Colorectal, Female Breast, Cervical, Liver, Lung, Melanoma, non-Hodgkin lymphoma and Prostate • Measure: Age-adjusted rate, Risk Probability and Population Density • Outcome: Incidence, Mortality and Late Stage
Identify differences among populations	• Stratification: Sex and Race/Ethnicity • Stratification subgroup: Sex (Male, Female) and Race (White, Hispanic, Black, Asian and Pacific Islander, American Indian and Alaska Native)
Identify temporal change	• Stratification: Year Group • Stratification subgroup: Years (2006-2010, 2011-2015, 2016-2020), Sex and Year (Male 2006-2010, Male 2011-2015, Male 2016-2020, Female 2006-2010, Female 2011-2015, Female 2016-2020).
Identify high-burden or low-burden units	• Filter by: Top n units, Bottom n units, AAR Percentiles (90th, 95th) and Risk Probability (top 50%, 60%, 70%, 80%, 90%, 95%).
Export data	• Enable exporting the filtered data as a CSV file
Export map	• Enable exporting the map of the current view
Map Panel	
Indicate uncertainty measurement	• Define the low, medium and high levels of uncertainty based on the AAR standard deviation with quantile classification and visualize the classes with three spacing visual variables
Overlay	• Add referenced overlay (county borders, roads and border and city labels) to help users locate specific areas • Add overlay (superfund sites) to indicate potential risk factors • Add overlay (public health region) to indicate healthcare service

Classification	• Use standard deviation classification for age-adjusted rate to indicate units with relative cancer burden that are above or below the state average
Legend	• Show a line indicating the state average level
Terminology explanation	• Add an annotation to explain the estimates meanings • Add tooltips to the interface elements, such as dropdown lists, buttons, etc.
Map interactions	• Hover on regions for more information. • Zoom (in or out within a specific area) and pan the map within a boundary. • Select multiple ZCTA/ counties at the same time (select specifically to show in the table)
Data Table Panel	
Data table	• Show values of filtered units in a table • Show values of selected units in a table • Dynamically link the table and the map. • Click a row to highlight the corresponding feature on the map. Double-click to zoom to the highlighted feature. • Click a feature on the map to highlight the corresponding row in the table.

Table 1. Core functional requirements identified during the needs assessment study are highlighted in black, while extended requirements identified during the usability evaluation are highlighted in orange

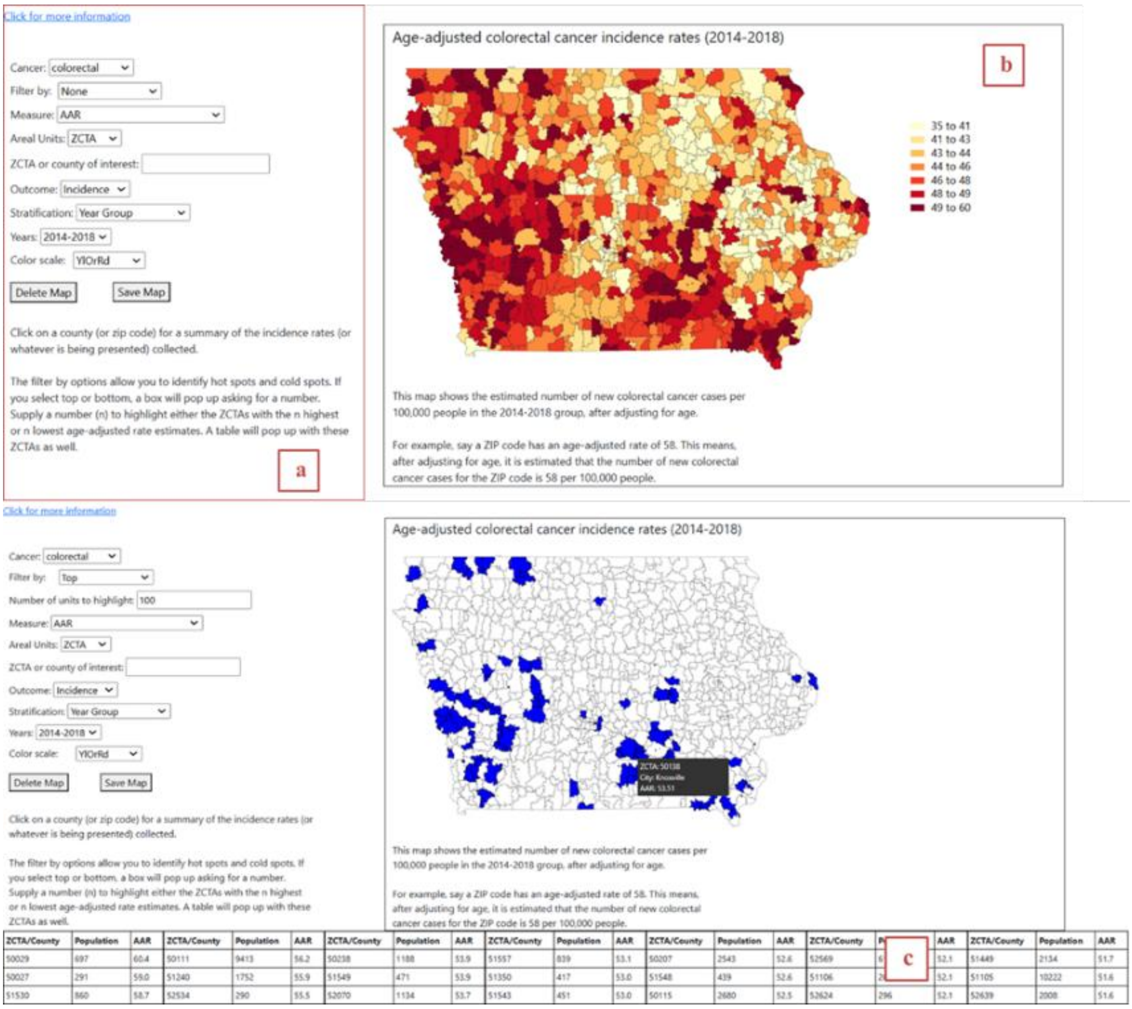

Figure 2. The Alpha Version of CAMSA. Designed to address the core functional requirements identified in the needs assessment study, this figure displays three interface panels: (a) the Data Configuration Panel, (b) the Map Panel, and (c) the Data Table Panel, which appears when users apply the “filter by” option to highlight high- or low-burden units.

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Measure	Terminology Explanations	Terminology Examples
Age-adjusted Rate	This map shows the estimated number of new colorectal cancer cases per 100,000 people in the 2014-2018 group, adjusted to the 2010 US Census age distribution.	For example, say a ZCTA has an age-adjusted rate of 58. This means, after adjusting for age, it is estimated that the number of new colorectal cancer cases for the ZIP code is 58 per 100,000 people.
Risk Probability	This map shows the measure of evidence of elevated risk for colorectal cancer for the 2014-2018 group, after adjusting for age. Values greater than 0.5 mean the estimated risk is above the state average and values below mean the risk is below the state average. Values closer to 1 signify the highest risk while values closer to 0 mean the lowest risk for the location in the group.	For example, suppose a ZIP code has a risk probability of 0.05 for colorectal cancer. This means the risk for colorectal cancer in the ZCTA is well below the state average.

Table 2. Notes of terminology explanations and examples for Age-adjusted Rate and risk probability, using colorectal cancer incidence for the 2014–2018 period as an example.

4.3 Extended Requirements and Beta Version

Feedback from post-development focus groups and surveys highlighted the effectiveness of the three interface panels in helping users identify cancer burden and differences among stratification groups. Participants appreciated the granular-level data provided by small-area estimates, particularly for cancer burden identification at the community level. They found the ability to configure multiple outcomes (incidence, mortality and late-stage incidence), highly useful, and commented that explanatory notes were especially helpful in aiding data interpretation by clarifying terminology unfamiliar to some users, particularly the general public. Survey results indicated that 71% of participants intended to use CAMSA to highlight hotspots or clusters, 71% for community or public health assessments, and 53% for presentations or grant writing. Additionally, User feedback suggested several enhancements to improve usability and support advanced analysis and communication (Table 1, highlighted in orange):

- **Data Configuration Panel (Figure. 3a):** Participants requested a data export option for external analyses and a high-resolution map export option for reports and presentations. In the beta version, we added an export section for users to export data as a Comma-Separated Value (CSV) file and export the map of the current view.
- **Map Panel (Figure. 3b):** Public health professional and researcher participants emphasized the need for confidence intervals to better evaluate the uncertainty of the estimates. To address this, the beta version incorporated the standard deviation of age-adjusted rate, derived from Bayesian hierarchical modelling, as a measure of uncertainty. This attribute comprises three classifications—low, medium, and high; the 33.33% quantile separates low from medium uncertainty, and the 66.66% quantile separates medium from high uncertainty. We visualized the uncertainty layer using spacing and transparency as visual variables, as shown in Figure 4. Densely spaced lines with full opacity represent high uncertainty, while widely spaced lines indicate medium uncertainty. Areas with low uncertainty are left without lines for clearer interpretation. Users can choose to overlay the uncertainty layer on the cancer burden layer to explore their bivariate relationships. Participants also suggested including referenced overlays to help locate specific areas, indicate potential risk factors, and identify healthcare service regions. Additional feedback on the map design included suggestions to change the classification method and add an annotation facilitating comparison to the state average. Other suggestions for enhancing map interaction included adding zooming, panning and feature selection to improve users' ability to effectively explore and analyze small area units. We resolved these usability suggestions in the beta version of CAMSA.
- **Data Table Panel (Figure. 3c):** Participants expressed the need to search for specific ZCTAs or counties to improve exploration and analysis. In response, we added a search function to the table panel, allowing users to identify the cancer burden of specific units. Additionally, we implemented linked interactions, enabling users to locate specific units from the table on the map and identify features from the map in the table to access detailed attribute information.

Sixty-five percent of survey respondents indicated they had the capacity to implement CAMSA within their registry setting. To support the implementation process, 32% of respondents expressed a need for training videos, 32% required one-on-one support with research staff, and 29% requested a frequently asked questions page. These results suggested the need to develop and maintain resources to better support the implementation of CAMSA.

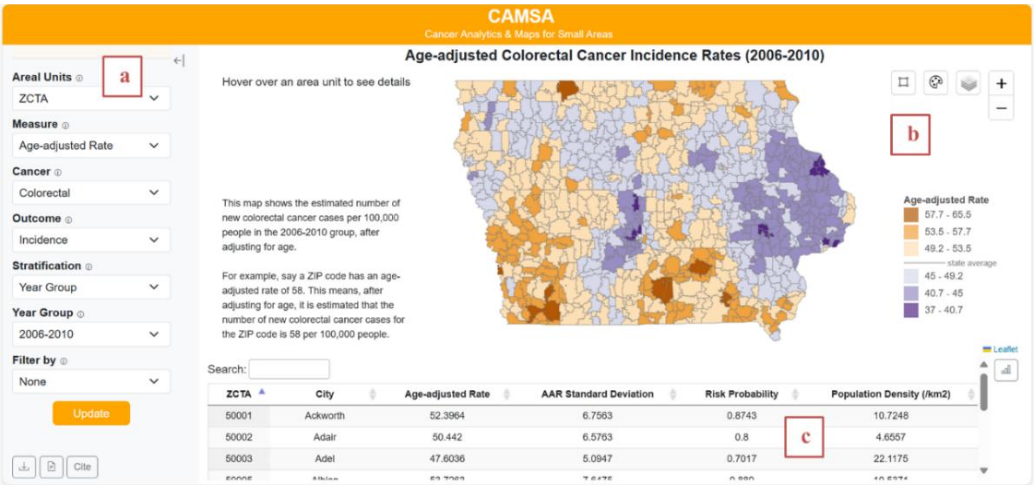

Figure 3. The Beta Version of CAMSA. This version retains the core functional requirements while integrating extended requirements identified during usability evaluation studies. It features three interface panels: (a) the Data Configuration Panel, (b) the Map Panel, and (c) the Data Table Panel

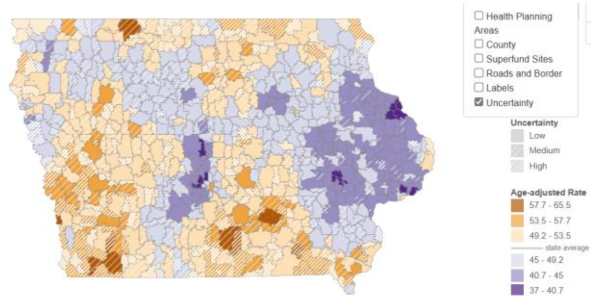

Figure 4 The uncertainty layer overlaid on the cancer age-adjusted rate layer in the Beta Version of CAMSA.

5. Discussion

The UCD approach proved effective in designing and developing CAMSA to ensure it meets the diverse needs of different end users. The formative needs assessment enabled us to formalize user profiles and core user requirements to identify tool features needed by different end users, guiding the development of the alpha version. The interviews and focus groups were effective in identifying user needs during the early design stage when we had limited understanding of potential users. Subsequently, the post-development focus groups validated the effectiveness of the core functionalities in the alpha version and identified additional functionalities to enhance usability. Through group discussions, we identified requirements that were consistent among group members, as well as divided opinions like adding uncertainty measurements. The implementation capacity surveys enabled us to gather feedback from professional users from cancer registries based on the alpha interface, which helped us refine their use cases and understand the capacity for future implementation of CAMSA across cancer registries. We prioritized the requirements gathered from focus groups and surveys and implemented the improvements in the beta version.

The focus groups revealed a divided opinion among users regarding the presentation of information, particularly uncertainty measurement versus narratives for data interpretation. Professionals and researchers emphasized the necessity of incorporating uncertainty measurements, such as 95% confidence intervals, which differ from the uncertainty metrics employed in our model (i.e., the standard deviation of age-adjusted rate estimates). On the other hand, the general public preferred a simpler interface and favored narratives to help them interpret the key insights from the map. A key concern from users on the uncertainty measurement is the potential for misinterpretation. In particular, there were concerns that the general public may incorrectly interpret values on the map as exact values instead of statistical estimates. More importantly, the general public is often more interested in learning concrete facts derived from the estimates rather than discussing uncertainties. To address these divergent needs, we have considered implementing a dual-interface approach. A basic version would include clear explanatory notes to balance the need for actionable insights with clarification of statistical uncertainty to those unfamiliar with these concepts. An advanced version could provide detailed definitions of uncertainty measurements, as well as more in-depth features like the ability to download estimates and maps.

For future UCD processes, we will involve direct user interactions with CAMSA to understand how different end users interact with the tool. For example, think-aloud studies could be conducted with the general public, professionals and researchers to distinguish between basic and advanced interface needs. Interaction studies may be used to assess the accuracy and efficiency of users in completing various tasks with CAMSA. Additionally, eye-tracking metrics could be measured to analyze users' visual behaviors during the interaction, which could help identify differences between effective and less effective responses.

In addition to requirements prioritized in the alpha and beta versions, we also identified functionalities from the UCD process and planned to incorporate them in the next iteration of CAMSA. We will add additional filtering options (e.g., rurality) to enable more diverse cancer burden exploration and health disparity identification. For users interested in identifying disparities in resource accessibility and planning targeted resource allocation, we will include overlays related to screening practices and access to care. Additionally, we will implement functions to calculate differences between stratification groups, such as sex or race/ethnicity, to help users quantify disparity more effectively. Furthermore, the next iteration will prioritize the need for risk factor analysis by integrating area-based social variables such as socioeconomic status, environmental exposures, social vulnerability factors and migration patterns with multivariate mapping.

6. Conclusion

This paper details the early stages of the design and development process of CAMSA, guided by a UCD approach. The goal of this project is to develop a visual analytics platform capable of revealing small-area cancer burden and health disparity that is accessible and practical for diverse end users. We included a pre-development needs assessment study and two post-development usability evaluation studies. We identified three end-use groups – the general public, public health professionals and researchers – who anticipated using CAMSA for five primary use cases: cancer burden exploration, health disparity identification, risk factor analysis, customized spatial and statistical analysis, and communication and collaboration. We developed the alpha and beta versions of CAMSA based on requirements formalized through user studies and provided opportunities for further development. As we continue to improve CAMSA with UCD, future iterations will focus on incorporating functionalities for risk factor analysis, enhancing usability, and supporting implementation.

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8. Acknowledgement

This research has been supported by funding from National Institutes of Health (U01CA258400), University of Iowa Holden Comprehensive Cancer Center (3P30CA086862) and National Cancer Institute (HHSN26120130010I, Task Order HHSN26100005; HHSN261201800014I, Task Order HHSN26100001; HHSN261201800013I, Task Order HHSN26100001)