Reducing Health Research Information Inequities: A Strengths-Based Design Approach with Alaska Native and American Indian Communities

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Abstract

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American Indian and Alaska Native (ANAI) people have experienced a history of unethical and exploitative health research practices, such as being exposed to procedures without informed consent and having research results disseminated without community input or approval. Oversights like these increase the need for transparency, community representation, and accountability in research at all stages from project conceptualization to results dissemination. Moreover, ANAI have been under-represented in large national health research initiatives—such as NIH's *All of Us* research program—and have only recently started being consulted in meaningful ways about how best to implement health research or disseminate actionable findings relevant to local community context.

For many researchers, the primary method of disseminating research results is to submit manuscripts to peer-reviewed journals or conference presentations, which essentially limits their audience to academic scholars. Limiting dialogue between

community stakeholders and researchers, many of whom may be unacquainted with community perceptions of health or community systems of sharing information, decreases the likelihood that research will be implemented at a community level. This lack of engaged communication can negatively impact community health outcomes. New methods and technologies for respectful and culturally responsive health research results dissemination communication are needed to help researchers engage diverse participants and to improve service to these communities. Reliable health research information supports wellness, but if that information is not presented in ways that are understood and contextualized, it has less community benefit and can also perpetuate widespread misinformation about health and well-being.

Though there has been extensive progress with ANAI community engagement in health research, only limited research has explored collaboration specifically with the results dissemination process. Moreover, limited user-centered design research has been conducted with and for ANAI communities.

For this dissertation, I developed an Indigenous Community-Centered Design (ICCD) approach to co-design and evaluate an ANAI stakeholder collaboration tool for health research results dissemination and communication. The ICCD approach incorporates community-engaged and Indigenous research approaches with community-centered and participatory design methods. In the first part of my research, in study 1, I used user-centered design approaches to establish a value-informed conceptual framework to support future design activities. Next, in study 2, I integrated strengths-based approaches with participatory design and speculative design methods to co-design a low-fidelity

prototype for collaborative results dissemination and communication. In my final study, I conducted a pilot study of the low-fidelity prototype, evaluating it for feasibility and acceptability in ANAI communities.

The ICCD approach provides an example of integrating Indigenous community-engaged research approaches with user-centered design, drawing on community strengths. This research supports improved research communication and has the potential to enhance ANAI trust in health research, increasing the impact of health research overall.

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Chapter 1: Introduction

American Indian and Alaska Native (ANAI) people have been conducting research even before Western empirical methods were established. For example, before colonization and Russian acculturation, Unangax (Aleut) people had an elaborate calendar system that factored in the natural environment and when the natural environment and animals were at certain points such as, when birds are laying eggs or when seals are skinny from the winter. These systems guided when the best times were to go hunting and gathering. It took exceptional observation and documentation aptitude to develop these systems of knowing. These methods took into consideration the world around them and the connection between the physical and spiritual worlds. However, research has not always been beneficial to ANAI communities and more recently we have experienced a history of unethical health research conduct. This disreputable research has imposed stereotypes on Indigenous people (i.e. drunk Indian, spiritual Native motifs) and research that has historically benefitted individual researchers or specific research institutions instead of benefitting the communities where the research was conducted[1]. A prominent example is an early-1990's diabetes research study conducted in the Havasupai community[2]. In this study, Havasupai tribal authorities sought the expertise of a human genetics researcher at the Arizona State University to evaluate the potential genetic causes for high rates of diabetes in their community. The study concluded that there was "too little variation among tribal members' genetics to conclude the incidence of disease among them was genetics-related."[3]. This was a valid result and fulfilled the community's request for research support. However, in addition to using the genetic samples collected for the diabetes study, researchers also used the samples for additional research on conditions such as schizophrenia and incest. These additional analyses were performed without consent from individual participants or the Havasupai Tribal leadership or community. Furthermore, they did not directly share the results of these studies with the community or involve community members in the research process. It was only a coincidence that the community discovered that further studies utilizing these biospecimen were conducted. These unethical research practices resulted in

Havasupai Tribal officials suspending any research requests from Arizona State University in their community. It also prompted systematic changes to informed consent procedures and increased United States Indigenous community involvement in research processes. This example is one of many in which ANAI community members have been harmed by research practices.

As a result of actions like these, many ANAI communities are wary of researchers and have established their sovereign rights over research by developing systemic practices to ensure research that is conducted in their communities is overseen by Tribal authorities. This often involves direct ongoing collaboration to facilitate transparency in the research process. However, other than using traditional academic dissemination methods (i.e. journal articles, conference presentations), limited progress has been made to ensure research results are returned to participants or otherwise shared with non-academic community audiences[4]. Studies suggest that research participants and community audiences *want* to receive research results and propose that participants have a *right* to receive them for contributing to the research[5, 6]. Still, sharing comprehensible health research results with non-academic communities is often neglected or done ineffectively[7]. For many researchers, the primary method of disseminating results is to submit manuscripts to peer-reviewed journals or conference presentations which essentially limits their audience to academic scholars[8-10]. Limiting dialogue between community stakeholders and researchers, many of whom may be unacquainted with community perceptions of health or community systems of sharing information, decreases the likelihood that study results will be implemented in communities[10]. New methods and technologies for respectful and culturally responsive research results dissemination are needed both to help researchers engage diverse participants and to better serve those communities.

Community Collaboration and Research Sovereignty

Community collaboration and research sovereignty in ANAI health research has become the standard, but limitations are still prevalent calling for a need for new methods to attain more contextually focused research dissemination strategies. As an outcome of ANAI

communities' rights for Tribal research sovereignty, community engagement in research has become increasingly prominent[11, 12]. Indigenous community members are often engaged throughout the research process. This comprises collaboration that occurs during the entire research process including conceptualizing research topics, developing research questions, collecting, analyzing, and interpreting data, and disseminating study results[8, 12-14]. Ongoing multidirectional communication encourages trust and allows communication to flow so information remains relevant to the community[14-17]. For ANAI communities this includes relevance to local context including local values, knowledge, and expertise[18-20]. Approaching dissemination as a collaborative community-researcher dialogue can strengthen community trust in research while enhancing researchers' understanding of community concerns and perceptions of research[14, 20, 21].

Technology Tools for Results Dissemination

Internet-based and other technological tools (i.e., social media, podcasts, interactive websites, video, and mobile applications) have potential to increase opportunities for disseminating research results to non-academic community audiences more broadly than through traditional means (e.g., journal articles, conference presentations) and possibly with more creativity and collaboration. Yet, few studies have been conducted that explore using technologies to share research results with non-academic community audiences, let alone with ANAI communities. Collaborating with ANAI community members on strategies for sharing research results in these ways makes sense. However, successful collaboration depends on how strategies are implemented, how accessible physical technology is (including hardware and software), and how involved community members are with developing those strategies for use with their communities. If developed appropriately, technology tools have potential to facilitate collaborative results dissemination. However, sharing research results poses challenges, particularly in relation to which results to share and what information participants want or can absorb from the results[22]. Success will require innovations in culturally sensitive methods and tools that support regular active engagement in developing and implementing these forms of dissemination.

In this dissertation, I developed an Indigenous Community-Centered Design approach to explore three primary areas to support improved research results dissemination with ANAI communities. First, I explored ANAI community values for community research collaboration in general and, more specifically, related to health research results dissemination. I used this knowledge to generate a conceptual framework that was used to guide the development of participatory design sessions to co-design a dissemination prototype for ANAI communities. Finally, I conducted an implementation evaluation and piloted the prototype to explore feasibility and acceptability of the dissemination tool.

Dissertation Aims

To amplify partnership, equity, and dialogue, I conducted a community-centered design[23] study and developed an Indigenous Community-Centered Design approach, which integrates Indigenous and community-engaged research approaches with user-centered design, to advance a framework for collaborative health research results dissemination communication in ANAI community contexts. Using participatory design and value-sensitive design I explored Native community results dissemination values. Value-sensitive design is an adaptable user-centered approach that engages moral and ethical considerations for technology design[24]. Participatory design seeks to democratize information technology use and innovation [25, 26]. Core tenets of participatory design include giving stakeholders meaningful influence in design and providing mutual learning opportunities between researchers and stakeholders [27]. Ideally, effective design sessions give stakeholders the ability to share their critical feedback on design solutions, create insight into ideas and prototypes, and understand design phases and concepts[28].

For this dissertation I used the Indigenous Community-Centered Design approach to address three specific aims as follows:

Aim 1: Define ANAI stakeholder values for collaborative health research results dissemination. I used a value-sensitive design framework to conduct participatory co-design workshops to explore ANAI stakeholders' values for research collaboration in general and for health research results dissemination.

Aim 2a: Co-Design an ANAI culturally responsive prototype for collaborative health research results dissemination and communication. I used a participatory design and speculative design approach to co-design a technology dissemination communication tool with ANAI people. Four design sessions were held with ANAI community members to co-design prototypes. Key concepts and themes from design data such as risks and benefits of using technology to collaborate on results dissemination and prototype preferences were qualitatively analyzed.

Aim 2b: Develop and evaluate prototype feasibility and acceptability in an ANAI community-based setting. Following the Aim 2a design sessions, I worked with an undergraduate research assistant to develop a low-fidelity prototype, informed by Aim 2a data collection activities, and conducted a pilot study evaluating the prototype.

Dissertation Setting

My research data collection took place in 2 locations, Anchorage, AK at the Southcentral Foundation from 2022-2024 and Seattle, WA at the University of Washington during the 2024 First Nations Annual Spring Powwow. The settings for these locations are provided here.

Southcentral Foundation (SCF)

Corporate Overview. SCF is a nonprofit healthcare organization serving ANAI people in the Anchorage Services Unit (ASU) in southcentral Alaska under the tribal authority of Cook Inlet Region Incorporated, an Alaska Native Claims Settlement Act Regional Corporation. The ASU includes both urban and remote rural areas (60 villages, most with fewer than 500 residents and unconnected to the road system) with 229 federally recognized tribes. Most of the 65,000 ANAIs served by the organization live in Anchorage and surrounding areas.

SCF's corporate headquarters are located in Anchorage on the Alaska Native Health Campus (ANHC). The seven-member all AN Board of Directors serves as SCF's chief policy-making body and exercises overall control and management of SCF's affairs. The President/Chief Executive Officer reports to Board, leads the Office of the President, and

supervises Vice Presidents who lead six divisions (Executive and Tribal Services, Resource and Development, Organizational Development and Innovation, Finance, Medical Services, Behavioral Services).

SCF's values and commitments to ANAI's as embodied in its Mission, Vision, and Corporate Goals guide process and system design/redesign as well as employee actions and behaviors. (Table 1).

Table 1. SCF's Vision, Mission, and Corporate Goals

Vision	A Native Community that enjoys physical, mental, emotional, and spiritual wellness.
Mission	Working together with the Native Community to achieve wellness through health and related services.
Corporate Goal 1: Shared Responsibility	We value working together with the individual, the family, and the community. We strive to honor the dignity of every individual. We see the journey to wellness being traveled in shared responsibility and partnership with those for whom we provide services.
Corporate Goal 2: Commitment to Quality	We strive to provide the best services for the Native Community. We employ fully qualified employees in all positions, and we commit ourselves to recruiting and training Native staff to meet this need. We structure our organization to optimize the skills and contributions of our employees.
Corporate Goal 3: Family Wellness	We value the family as the heart of the Native Community. We work to promote wellness that goes beyond absence of illness and prevention of disease. We encourage physical, mental, social, spiritual, and economic wellness of the individual, the family, the community, and the world in which we live.
Corporate Goal 4: Operational Excellence	We develop and improve our operations that support delivery of services to customer-owners.

The needs and wants of ANAI's served are elicited, heard, and integrated into decisions, structure, and process through a variety of listening posts to include ongoing customer satisfaction and other surveys, interactions with leaders at community events, social media, focus groups for special purposes (e.g., redesigning a service), needs assessments, and advisory committees. Many employees are also eligible for services and are encouraged to provide input and feedback through these listening posts, to participate in functional structure committees, and to participate in strategic planning and decision making within their respective departments and divisions.

Nuka System of Care: SCF operates the Nuka System of Care, a customer-driven, relationship-based health care system. "Nuka" is an AN word for strong, giant structures and living things. The Nuka System of Care includes over 80 health and wellness programs within more than 30 facilities staffed by more than 2,400 employees. More than half of all employees (54%) are of ANAI heritage. Health and health-related services include primary care, behavioral health, dentistry, pharmacy, optometry, audiology, complementary medicine, traditional healing, physical therapy, health education, home-based services, as well as elder and youth programs. Most services are ambulatory except for residential and day treatment behavioral services.

Alaska Native Medical Center (ANMC): SCF co-owns and co-manages this 150-bed hospital on the ANHC in Anchorage. ANMC provides inpatient services to ASU residents and tertiary and specialty services to ANAI people statewide. ANMC services are provided by more than 250 Board-certified physicians and over 700 nurses on staff. Forty-two percent of all active users of Indian Health Service (IHS) and IHS-compacted facilities throughout the State of Alaska use ANMC services.

Primary Care Services: Interdisciplinary, primary care teams are the underpinning of SCF's Nuka System of Care, a tier 3-designated medical home model that emphasizes the importance of the relationship between patients and integrated care team members. Care teams include a provider (MD, DO, ARNP, PA), 1-2 certified medical assistants, integrated specialists (e.g., women's health, pediatrics, behavioral health consultants, psychiatrists, pharmacists), a full-time nurse who focuses on care coordination, and an administrative assistant who provides case management support.

The Anchorage Native Primary Care Center (ANPCC) on the ANHC houses 39 primary care teams. The ANPCC also houses laboratory, radiology, pharmacy, women's health, and specialty behavioral health clinics.

Health Education Services: Health education services are provided at the Mount Marathon Building on the ANHC and in the VNPCC. Services include individualized health coaching, group classes educational workshops, support groups, and special health events

Research: The SCF Research Department (RD) is situated within the Organizational Development and Innovation Division. SCF has demonstrated substantial institutional commitment to research focused on conditions that affect the health of its customer-owners.

University of Washington First Nations Annual Spring Powwow

The First Nations Annual Spring powwow takes place on the campus of University of Washington (UW) each Spring. The powwow is an event that celebrates ANAI culture and communities and is organized by UW undergraduate students with the support of the local Seattle community, UW staff and alumni, and donor contributions.

Personal Background and Positionality

The research in this thesis is the result of some core research information issues I have been pondering throughout my time as an Alaska Native health researcher. A decade following the start of my research career I began experiencing apprehension about my work as a health researcher. I started to become disheartened by patterns of research results dissemination that were limited to academic audiences. These reflections came full circle when I came across an article on a family member's table concerning a mitochondrial DNA study conducted in the community I grew up in, Atka, Alaska. The article was submitted to a regional newsletter as a means of sharing results with my home community and other Unangax (Aleut) communities where the study was conducted. Technical terms like "polymorphism", "haplogroup" and "CIR60" were interspersed throughout the article, with no explanations included. I wondered if the researchers considered explaining study results in non-technical language, or if they consulted with community members before even publishing the results. I talked with family members about the article, they did not understand the study, which solidified my concerns that appropriate community

engagement did not happen in determining how to share results back to the participating communities. These reflections led to my interest in the information science profession and a desire to study community engagement in research dissemination using culturally meaningful and reciprocal approaches. I thought about how community members could be more involved in results dissemination. I reflected on how technology could facilitate community involvement in research results interpretation, communication, and dissemination.

While working at the Pacific Institute for Research and Evaluation (PIRE), I co-authored my first substance abuse intervention publication which presented results of a video-recorded observation study of a teacher-led substance abuse prevention curriculum to adolescents in rural Alaskan communities. I also provided research support for a randomized control trial using environmental strategies for decreasing youth substance abuse. It was these projects that ignited my interest in improving the results dissemination process for community-based audiences from a researcher perspective. In two of these projects, study teams prepared results presentations tailored to community-level data that represented over 20 participating communities. The results were shared during public community presentations and to local school staff who delivered the intervention in the communities. I came to realize that the results dissemination strategies we employed, and many other methods I had previously encountered as a researcher, were not as responsive to community-based audiences as they could be. Most of the local community events had poor attendance, with limited representation from community members. Results were also presented as they might be for an academic audience, including the use of statistics, charts and graphs. Though we did explain the data using non-scientific language, it was still lacking from my perspective. This was seen in how disengaged or disinterested many of the audiences were. For this reason, research lessons learned were less likely to be implemented locally which reduced community benefit of this research.

As a researcher at the Southcentral Foundation (SCF) I had additional opportunities to lead research coordination and contribute to academic and community publications. While at SCF, I conducted behavioral health services research on alcohol misuse, trauma informed

care, palliative care communication, depression management, and suicide prevention. I supported senior level researchers in planning, implementing, and disseminating results for these studies. My first lead-author publication was a manuscript in a special issue on research dissemination in Alaska Native communities. The manuscript explored disseminating results of a study on a depression-management, decision-support, mobile-technology tool in a primary care setting to Alaska Native communities[30]. Community participants were asked to evaluate an infographic used to disseminate study results and provided insight into the use of infographics for sharing research results at a community level. Small group discussion participants provided constructive feedback about why depression-related research results should be shared; how they believed results should be best shared; who results should be shared with; when and where results should be shared; and to what level results should be shared. One key finding from this study was that stigma associated with depression treatment may be assuaged if results are shared in a way that normalizes support for depression treatment.

Additionally, I co-authored two more dissemination-related publications in the same special issue. One manuscript was about disseminating trauma-related research to community audiences[31]. In this study, we learned that community members wanted results to be shared with the entire community in ways that reach all Alaska Native audiences. They also wanted results to be used to improve care for trauma and related symptoms and wanted to be provided with study updates at each stage of the study. The other publication I co-authored included an overview of ongoing challenges to engaging and disseminating research in Alaska Native communities as a way to introduce the emphasis of the special issue[14].

My experience working on these studies further developed my interest in exploring results dissemination, particularly using health information technologies. I became more interested in developing community health informatics tools that would help facilitate Alaska Native community engagement in research, and particularly the results dissemination processes which led to the research I have done for this dissertation.

Dissertation Overview

My dissertation thesis is organized into 8 chapters as outlined below. In some cases, chapters included in this document are from published manuscripts or those I have submitted for publication to peer-reviewed venues. I include a note and citation at the beginning of each chapter if it was previously published (Chapters 2, 6, & 4) or submitted for publication (Chapter 7). Additionally, I've included a summary and highlighted contributions at the end of each chapter.

In **Chapter 2**, I share insights about why ANAI communities should be more engaged in the scientific research process than has typically been standard. I highlight the importance of research sovereignty and how postcolonial theory has been previously used in health research with ANAI communities and how it is helpful to my research.

In **Chapter 3**, I provide context about the use of participatory design with marginalized communities, including some possible challenges in its use with ANAI communities.

In **Chapter 4**, I present results from study Aim 1. I share a value-sensitive design study exploring ANAI stakeholder perspectives on using technology to support ANAI community collaboration in research dissemination. I also present a value-based conceptual framework for collaborative research results dissemination which was used to support development of the design activities in Aim 2 co-design sessions.

In **Chapter 5**, I present results from co-design activities for study Aim 2a, including a summary of findings that grounded the prototype in the co-design data.

In **Chapter 6**, I introduce the strengths-based research approach I used in my research studies for this dissertation, including an example of how the approach was used in a design activity during co-design workshops. I also include a strengths-based analysis of photo elicitation data as an example highlighting ANAI community strengths to support the design process.

In **Chapter 7**, I share information about the Indigenous Community-Centered Design approach that I compiled and used throughout my dissertation studies. I also provide results of Aim 2b's prototype testing and evaluation.

Finaly, in **Chapter 8**, I conclude this dissertation by describing how I fulfilled my dissertation aims, followed by a discussion on the contributions of my research. I also discuss the limitations of my research and share possible future research opportunities.

Chapter 2: Collaborative Research Results Dissemination- Applying Postcolonial Theory to Indigenous Community Contexts

This research was previously published (see citation below)

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Abstract. Community engagement in research has become increasingly important; it is essential for research conducted with Indigenous communities. In some cases, community members are receptively engaged in research from beginning to end, but this is inconsistent. Community collaboration during the results dissemination process is an element of engagement that is consistently overlooked or otherwise ineffectively executed. The concept of decolonizing research and the postcolonial theoretical foundations of decolonization are explored in this paper. Decolonizing research involves conducting research with Indigenous communities that places Indigenous voices and epistemologies at the center of the research process. This paper considers a decolonization framework to examine Native American community collaboration in the research results dissemination process including recommendations for applying postcolonial theory in the design of technologies to facilitate collaborative research results dissemination.

Keywords: Indigenous research, results dissemination, postcolonial theory, decolonization, collaboration.

Introduction

A large number of research studies conducted in Indigenous communities has excluded significant Indigenous voice [1]. Nevertheless, in the past several decades, there has been an emphasis on decolonizing research conducted in Indigenous communities, which includes active community collaboration. This comprises collaboration that occurs during the entire research process including conceptualizing research topics, developing research questions, collecting, analyzing, and interpreting data, and disseminating study results. However, other than using traditional academic dissemination methods (i.e. journal articles, conference presentations), limited progress has been made to ensure research results are shared with participants or otherwise disseminated to non-academic community audiences [4]. Studies suggest that research participants and community audiences want to receive research results and propose that participants have a right to receive them for contributing to the research [5, 6]. Still, sharing comprehensible research results with non-academic

communities is often neglected or done ineffectively [7]. For many researchers, the primary method of disseminating results is to submit manuscripts to peer-reviewed journals or conference presentations which essentially limits their audience to academic scholars [8-10]. Limiting dialogue between community stakeholders and researchers, many of whom may be unacquainted with community perceptions of research or their systems of sharing information, decreases the likelihood that study results will be locally implemented [10].

Internet-based and other technological tools (i.e., social media, podcasts, interactive websites, video, and mobile applications) have potential to increase opportunities for disseminating research results to non-academic audiences more broadly than through conventional means (e.g., journal articles, conference presentations) and possibly with more creativity and collaboration. However, few studies have been conducted that explore using technology tools to share research results with non-academic community audiences let alone with Indigenous communities. Collaborating with Indigenous community members on strategies for sharing research results would be appropriate. However, successful collaboration depends on how strategies are implemented, how accessible the physical technology is (including hardware and software), and how involved community members are in developing strategies for use within their communities. If developed properly, technology tools can potentially be used to facilitate collaborative results dissemination. Proper development and implementation will require regular active community engagement while also acknowledging power relationships. Postcolonial theory can be used to assess these barriers to development and implementation.

This paper examines research results dissemination in an Indigenous context using a postcolonial framework. The first section of the paper provides context for recent disreputable research conduct in Indigenous communities, including a case example of unethical research. This is followed by a grounding in historical foundations of decolonizing research leading into discourse on decolonization's postcolonial theoretical foundations. The paper concludes with a discussion on collaborative dissemination in Indigenous contexts including suggestions for decolonizing the research process by questioning positivist research approaches and promoting dialogue between researchers and

Indigenous community members concerning results dissemination and in using postcolonial theory to design technologies to facilitate dissemination collaboration.

Unethical Research Dissemination Practice

Indigenous communities have experienced a history of unethical research conduct such as data being collected without consent, disclosure of sacred Tribal information, and public reports of research shared without community approval. This disreputable research has imposed stereotypes on Indigenous people (i.e. drunk Indian, spiritual Native motifs) and research that has historically benefitted individual researchers or specific research institutions instead of benefitting the communities where the research was conducted [1]. A prominent example is an early-1990's diabetes research study conducted in the Havasupai community [2]. In this study, Havasupai tribal authorities sought the expertise of a human genetics researcher at the Arizona State University to evaluate the potential genetic causes for high rates of diabetes in their community. The study concluded that there was "too little variation among tribal members' genetics to conclude the incidence of disease among them was genetics-related."[3]. This was a valid result and fulfilled the community's request for research support. However, in addition to using the genetic samples collected for the diabetes study, researchers also used the samples collected as part of the diabetes study to conduct additional research on conditions such as schizophrenia and incest. These additional analyses were performed without consent from individual participants or the Havasupai Tribal leadership. Furthermore, they did not directly share results of these studies with the community or involve community members in the research process. It was only a coincidence that the community discovered further studies utilizing the biospecimen were conducted. These unethical research practices resulted in Havasupai Tribal officials suspending any research requests from Arizona State University in their community. It also prompted systematic changes to informed consent procedures and increased United States Indigenous community involvement in research processes. This example is one of many in which Indigenous community members have been harmed leading to research distrust. As a result of actions like these, Indigenous communities have taken ownership over research

by developing systemic practices to ensure research that is conducted in their communities is overseen by Tribal authorities. This oversight often involves direct ongoing collaboration to facilitate transparency in the research process.

Decolonizing Research

Unethical research activity such as the Havasupai case happened long before the example above. During worldwide exploration and colonization, Western European colonizers brought ideas, practices and methods for science and technology including how knowledge is recorded (classified and archived). Proponents of decolonization posits that colonizers viewed themselves as central to knowledge and "the arbiter[s] of what counts as knowledge and the source of 'civilized' knowledge" [32]. This view played itself out as colonizers established themselves as "experts" in the places they colonized, including expertise on the Indigenous people and lands they colonized. This was done through knowledge organization (i.e. archives, logs) that put colonizers at the center of knowledge production. Much of this organized knowledge production included appropriated Indigenous knowledge and procedures for assimilating or outlawing Indigenous cultural knowledge and practice deemed uncivilized, non-Christian, or in some way "other" than their own [32]. From a decolonization perspective, these actions were performed to dominate and hold control over colonized societies. What this effectively did was change the knowledge systems of Indigenous communities. Traditional knowledge was lost through forced assimilation, which attempted to extinguish language, culture and belief systems, or the knowledge was reshaped by Western thought, effectually restructuring much of the original intended meaning.

To counter the historical impacts of colonial control, many Indigenous communities have taken a decolonization approach to research. This process involves changing the power dynamics among marginalized communities by utilizing multiple epistemologies, ontologies and axiologies [33]. These practices support Indigenous community wellness by honoring Indigenous epistemologies, philosophies, beliefs, and values that counter the effects of colonialism [34-38]. This is done through challenging ideas that Western scientific methods

and epistemologies are the only true scientific methods which essentially depreciates Indigenous epistemologies as simple folklore [1]. Although Indigenous epistemologies are central to decolonization theory and should be incorporated in research practice, Western research methods and theories should not be precluded , but appropriately adapted to specific Indigenous contexts [32, 39]. For example, in some (not all) Indigenous communities, incorporating a narrative approach may be more appropriate than collecting data through using a validated survey instrument or even conducting a content analysis of interview data which parses out different pieces of an interview and by doing so may lose meaning without context found in the interview as a whole. Some Indigenous communities consider the entire story as important for establishing meaning which would be lost if only a part of that story were analyzed through qualitative analysis methods that isolates only selections of a whole interview.

Self-Determination

Self-determination is an integral component for decolonizing research. In the context of decolonization, self-determination involves actions towards shaping a "world according to terms chosen by oneself, or by a people collectively" [40]. For Indigenous communities, this entails constructing their own values and beliefs for what constitutes knowledge [39] and control over expressions of cultural heritage and intellectual property [41]. From a postcolonial lens, through self-determination, Indigenous communities now have more control and ownership over research conducted in their respective communities, how that research is conducted, and who is involved. This is not to say that non-Indigenous researchers are unwelcomed to conduct research in many Indigenous communities, but that they need to acknowledge the community's privilege to determine the research. An insistent reflexivity about who maintains control over decisions is required to effectively respond to self-determination [1, 42].

In the past several decades, Indigenous people have been reclaiming their languages and cultures. Prominent Maori scholar Linda Tuhiwai Smith refers to this as a phase of resistance and survival eventually leading to recovery as Indigenous peoples [32]. She notes that this

“sense of optimism…is often criticized by non-indigenous scholars, because it is viewed as being overly idealistic”[32]. Much progress has been achieved in Indigenous communities towards recovering Indigenous identities and showcasing resiliency. This can be seen in Indigenous communities where efforts are being made to revitalize language through educational programming and to learn traditional cultural practices (i.e. tattooing, weaving, traditional food preparation, dance). Related to this, Smith criticizes Western views about what it means to be an authentic Indigenous person and suggests that the “belief that Indigenous cultures cannot change, cannot recreate themselves and still claim to be Indigenous” only encourages marginalization [32]. This leads back to the importance of who determines what Indigenous culture and knowledge are, which, from a self-determination standpoint, should be Indigenous people.

Postcolonial Theory

Various decolonization processes are rooted in postcolonial theoretical traditions. Postcolonial theory broadly emphasizes systematic approaches to power and dominance over marginalized communities. This includes examining the influences of historical oppression on modern social conditions within marginalized communities [43]. Postcolonial theory situates itself amid other critical theories such as postmodernism, poststructuralism, feminism, and Marxism [44, 45]. These critical theories place emphasis on understanding how power “through advantage and disadvantage, operates based on historical positioning, class, race and gender” and how these power structures intersect to perpetuate control over marginalized communities [46]. Essentially, within an Indigenous community context, postcolonial theory attempts to show how colonization has influenced community deficits, such as racism, historical trauma, and social determinants of health. Some Indigenous scholars believe that postcolonial theory perpetuates Western researchers’ control over Indigenous epistemologies [43] and suggest that by focusing on the power relationships using a postcolonial lens, proponents may miss capturing Indigenous values such as those related to family, spirituality, humility and sovereignty [47].

But instead, imply that Western approaches could still be used if done while also honoring Indigenous values and epistemologies [32, 35, 37, 38, 48].

Indigenous Research Methodologies

Incorporating Indigenous research methodologies is a significant step towards decolonizing research. Many Indigenous scholars assert that Indigenous methodologies focus on collective community needs entrenched in holistic relationships between people, their values, beliefs, and connections to the physical world versus individual needs [32, 38, 39, 48]. Moreover, to explore these holistic relationships, research might instead incorporate traditional empirical approaches, such as observation, but knowledge may also be acquired through generational storytelling, elder-youth apprenticeships, and experiential learning in a practical setting [52]. In this sense, since knowledge is intertwined with daily existence, it can be difficult to categorize and systematically define with empirical approaches [35, 47]. In contrast to positivist social science approaches, where the goal of science is to predict and control behavior, Indigenous research methodologies do not prioritize predicting or controlling behaviors but focus on relationality between constructs such as people and their physical, social, and spiritual environment [1].

Nevertheless, Indigenous communities vary in many ways, such as different linguistic, geographic, legal, cultural, and social differences. No single epistemological approach should be considered as a remedy for all research conducted in all Indigenous communities as each community has its own characteristics, needs, and expectations. For instance, within the United States there are 578 federally recognized tribes [53] many of whom have similar histories of research misconduct, yet there is also considerable variation in social, political, and cultural practices within these communities, making a one-size-fits-all approach to research with Indigenous communities impractical. Moreover, Indigenous knowledge systems have been reshaped through acts of colonization and new knowledge systems were created and continue to be part of each Indigenous community's life. In this regard, decolonizing research also means acknowledging the history and knowledge shifts that resulted from colonization [40, 44]. These acknowledgments highlight the importance

of active collaboration with Indigenous communities to determine what works best for their unique circumstances.

Reacting to Western Positivist Research – Participatory Approaches

Traditional Western research methodologies, such as those rooted in empiricism and positivism can be used successfully in Indigenous communities depending on the research questions being asked and how they are implemented. However, the underlying epistemologies of these approaches are often counterintuitive to Indigenous epistemologies and are less likely to be successful unless they are adapted [1, 38] which regularly involves engaging Indigenous community members in developing local processes. Participatory research approaches, such as community-engaged research, community-based participatory research, and participatory action research lend themselves to decolonizing these processes. From a postcolonial perspective, participatory approaches can help to address power disputes by challenging dominant systems of knowledge and power [46]. However, not all community-engaged research distributes power equally. On one end of the continuum, research that is exclusively investigator-driven has much less community involvement, while on the other end of the spectrum, research driven by the community, includes much more community control [54]. Between these two points there are varying levels of power-dynamics over who has control over the research.

Conventional positivist research approaches have been criticized for not using Indigenous people's knowledge or empowering communities to create their own new knowledge in order to take action towards goals they determine are important [55]. Engaging community participation in the research process supports the decolonization process by placing the community in the role of knowledge provider, as educators and owners of the knowledge they share [39]. An Indigenous person may take the role of an independent research investigator and may or may not engage the community in the research process. Simply being an Indigenous researcher does not automatically entail the research being conducted engages the community. There may be hidden undercurrents, such as the researcher may not be invested in the community and have priorities that do not align with the community

wants or needs. For instance, their actions may be more motivated by research productivity (i.e., manuscripts, funding opportunities) than community expectations. Therefore, transparency measures should be implemented to shine a light on these dynamics.

Although a community-engaged research approach may be appropriate to utilize in Indigenous communities, there are also significant limitations from a postcolonial perspective. Assuming that a community-engaged approach equates giving power to a community is problematic as the concept of empowerment varies across cultures and communities [46]. Community members may be impartial to research or have different priorities to address that may not be addressed through a proposed research study. Moreover, there may be challenges in determining which community members have the authority to speak for the rest of the community. In some cases, the agents chosen to represent the community may establish their own dominance and control reinforcing colonial power relations [46, 66]. In addition to deep-rooted epistemological concerns, there are also technical limitations. Community engagement is a slow process requiring time to develop and maintain relationships which may present time limitations and financial constraints [11, 20, 67]. These restrictions are often unrealistic given funding agency expectations of timely progress for study outcomes, which do not often factor in relationship development or community collaboration [46]. Moreover, community priorities may shift and, if the research is no longer a community priority, then continued community engagement may falter [46].

Decolonizing Research Results Dissemination

As an outcome of many Indigenous communities' prioritization for decolonizing research, community engagement in research has become increasingly more prominent [11]. Indigenous community members are often engaged throughout the research process. However, effective collaboration during the results dissemination process has been limited [8,14]. Ongoing multidirectional communication encourages trust and allows communication to flow to encourage information is relevant to the community [14-17]. For Indigenous communities this includes relevance to local context including local values,

knowledge, and expertise [18-20]. Approaching dissemination as a collaborative community-researcher dialogue can strengthen community trust in research while enhancing researchers' understanding of community concerns and perceptions of research [14, 20, 21].

Potential for Using Postcolonial Theory for Results Dissemination Technology Design

Postcolonial theory has promise to inform active community engagement in the design of research dissemination technologies for Indigenous communities. Design activities could involve an acknowledgement of the social, political, and historical impacts of research on Indigenous communities. This framing can provide transparency and openness to discuss research experiences throughout the design process and provide context for design processes and products. Applying postcolonial theory can also contribute to understanding power dynamics between Indigenous design participants and researchers as well as power relations within their respective community. It may also be useful for understanding how a history of unethical research experience impact Indigenous participants' understanding of the research and dissemination processes. Understanding these relationships may help develop tools that encourage dialogue between researchers and participants. Postcolonial theory can supplement theoretical approaches, such as feminist theory to address how colonial and gender power dynamics impact research results dissemination and access to technology in Indigenous communities. Integrating Indigenous epistemological approaches may also be added to give community-level power to the design process. For example, the design process could include a storytelling component that integrates Indigenous oral traditions giving participants control of what they choose to share while aligning with their interpretations of the world around them. Engaging design participants in these ways may increase parity by supporting their role as educators and owners of the knowledge they choose to share.

Research that honors Indigenous knowledge while acknowledging researchers' learned biases towards what constitutes valid data is imperative for the conduct of ethical research

and design with Indigenous communities. Early colonizers did not typically acknowledge Indigenous contribution to scientific foundations [32]; in some ways, this is still the case with modern research. Encouraging transparent communication and collaboration during the research and design activities ideally promotes respect and validity for all knowledge systems (e.g., Western and Indigenous). As each community has its unique characteristics, eliciting feedback from Indigenous communities to provide direct response on how and in what ways they want to receive research results is imperative to make decisions on how technology should be used to disseminate research results to their communities. Community collaboration will undoubtedly uncover other issues that need to be addressed. This will require planning ahead of implementing technology-facilitated collaborative dissemination strategies. These plans should consider evaluating and continually reevaluating community interests in using technology, technological assessment of communities, analysis of potential partnership agencies, and capacity to implement projects.

Chapter 2 Summary and Contributions

This chapter explores the importance of decolonizing research conducted in Indigenous communities and focuses on collaborative dissemination of research results. I highlight the historical exclusion of Indigenous voices in research and unethical practices, such as the misuse of data without consent, exemplified by the Havasupai diabetes study. Practices such as those that occurred in that community have perpetuated research mistrust and prompted Indigenous communities to reclaim control over research through self-determination and systemic oversight.

I advocate for collaborative dissemination of research results, which is often overlooked, even in community-engaged research. I suggest using technology tools (e.g., social media, podcasts, interactive websites) to share findings with non-academic audiences, emphasizing the need for active community engagement in the design and implementation of these tools. Postcolonial theory is proposed as a framework to address power

dynamics, historical impacts, and ethical considerations in designing dissemination technologies. Incorporating Indigenous storytelling and oral traditions into the design process is recommended to honor Indigenous knowledge systems.

Ultimately, I underscore the importance of transparent communication, mutual respect, and community collaboration to ensure research benefits Indigenous communities and aligns with their unique needs and values.

The chapter makes several contributions:

1. **Highlighting Ethical Concerns in Indigenous Research**: I underscore the historical exclusion of Indigenous voices and unethical practices, such as the misuse of data without consent, exemplified by the Havasupai diabetes study. This serves as a cautionary example and emphasizes the need for ethical research practices.
2. **Advancing Decolonization Frameworks**: I explore decolonizing research by centering Indigenous epistemologies, values, and methodologies while adapting Western approaches to align with Indigenous contexts. I challenge the dominance of Western positivist methods and advocate for more participatory approaches.
3. **Focus on Results Dissemination**: I identify the lack of effective collaboration during research results dissemination and stress the importance of sharing findings with non-academic audiences, particularly Indigenous communities, in ways that are accessible and culturally relevant.
4. **Proposing Technology as a Tool for Dissemination**: I suggest technology tools to facilitate collaborative dissemination of research results and emphasize the need for community engagement in the design and implementation of these technologies.
5. **Application of Postcolonial Theory**: I introduce postcolonial theory as a framework to address power dynamics, historical impacts, and ethical considerations in research dissemination. This includes integrating Indigenous knowledge frameworks into technology design.
6. **Practical Recommendations to researchers**: I provide actionable suggestions for researchers, such as fostering transparent communication, engaging communities throughout the research process, and designing dissemination strategies tailored to specific Indigenous contexts.

Chapter 3: Reflections on Participatory Design with Historically Excluded Communities

This chapter has not previously been published.

To help provide additional context about my use of community engaged participatory design in my studies, it is important to provide additional context, highlighting the importance of community engagement in conducting research *with* and *for* ANAI communities. This chapter provides background on participatory design, and its use with historically excluded or otherwise marginalized communities.

I used community engaged approaches in my research that align well with postcolonial theory. Participatory design (PD) has been used extensively as an attempt to give affected users a say in design. However, among historically excluded or marginalized communities there have been some lessons learned related to design and power relations that are important to consider for my research. Below I highlight some of those lessons and then discuss how they are relevant to my research.

Participatory Design with Historically Excluded Communities

Participatory design (PD) is a user-centered design approach that seeks to democratize information technology use and innovation[25, 26] and is an approach, in theory, that aligns well with postcolonial theory. Developed in the 1970's in Scandinavia, core tenets of PD include giving stakeholders meaningful influence in design and providing mutual learning opportunities between researchers and stakeholders[27]. Ideally, effective PD sessions give stakeholders the ability to share their critical feedback on design solutions, create facilitator-led insight into ideas and prototypes, and understand design phases and concepts, all while having motivation to participate over time[28]. However, there are challenges to determining what gives stakeholders voice, what ensures mutual benefit and trust, what community decision-making and power structures are in place, and how PD is used. These challenges are particularly relevant for design with historically excluded

communities. The following provides some lessons learned from PD studies conducted with historically excluded and marginalized communities.

Community Context

As with any participatory activity, it is important to understand the contextual nuances of conducting PD with a historically excluded community, especially if the researcher is not already affiliated with the community. For example, Harrington et al. (2019) suggest that communities may perceive design and creativity differently from researcher/designers who are developing PD methods for implementation and typical PD materials, such as markers and post it notes may feel childish or belittling to participants[56]. They may also have a history of unjust research and governmental interference that needs to be acknowledged and designed for[56]. An essential step to awareness of community context is to spend time developing relationships with stakeholders and getting to know the community before initiating PD activity. Del Gaudio and colleagues [57] suggest a proactive approach involving careful contextual analysis of the community, discovering potential problems (from both the researcher and community perspective) and developing and implementing strategies to address those problems prior to starting PD activities. Awareness of context also includes understanding local culture, including how to approach participants and show respect in culturally-specific ways which can be achieved by spending time with different stakeholder groups, many of whom may not be the design's intended end user[58]. Furthermore, developing relationships before PD activity may also help uncover hidden agendas that may conflict with participatory activities[57]. For example, partnering agencies (i.e., NGO's) may use PD activities to leverage their own interests disregarding the community's input from the design sessions.

Trust

Forming mutual trust is also essential for maintaining participatory relationships. Without it, participants may not feel comfortable fully disclosing their stories for fear of retribution[56]. This trust building can occur through continuous dialogue and iterative reflection on community interpretations of technology, that may be helpful for uncovering local

frameworks to reference technology interaction which may be more sensible to community members than academic frameworks[59]. Moreover, community participants should be able to openly express opinions about existing and proposed designs[28] as they may be less likely to share opinions if they distrust or misunderstand the PD process or feel like they will be in trouble if they openly share. Pre-design activities intended to introduce design frameworks and stages can help develop understanding of the PD process which may encourage trust[57, 58]. Developing technology skills in the community can also help equalize relationships since participants are likely to be more comfortable talking about technology if they understand it from the context of the research activities[59]. Furthermore, researchers should also be flexible with their plans and have an openness to learn from community-proposed alternative methods, timelines, or logistics[60].

Stakeholder Decision Making and Benefit

Although PD provides opportunities to work directly with stakeholders impacted by a design challenge, it does not always lead to the most beneficial solutions. To help generate more useful designs, community members can identify components that are culturally relevant, meaningful, and contextually practical[58, 61]. In some historically excluded communities, stakeholders who were not the intended audience, such as elders[62] or family members[61] may be essential to include in the design process to reflect community social protocol, such as collective decision-making. However, direct stakeholder involvement in all aspects of the design is not always possible or even desirable to community members. For example, in rural Alaska, travel and accommodations to villages can be expensive and difficult to obtain, making it hard to engage the community. Air travel may only be available at certain times, telephone and internet services may not be reliable, and communities may not have enough lodging to support on the ground engagement. Similarly, Brough et al. [63] found that participants in a mobile platform codesign project for immigrant workers and organizers to share stories about their lives and social justice efforts perceived their contributions to the design process at varying levels. While some participants felt that they had limited contribution to designing the technological components of the design, all reflected a sense of meaningful participation in the graphical design features[63].

Ethics and Power Dynamics

These lessons learned point to the importance of understanding community participation and power dynamics in the process of PD. Exploring participant experiences of power and ability to participate in the design process provide insight into how they perceive their contribution to the PD process. Power dynamics play out in different ways with historically excluded communities and are certainly dependent on context. For the most part, the literature I reviewed promotes either a balanced researcher/participant partnership or community-led control over PD. Participation also typically includes an intermediary partnership with a local organization (i.e. NGO, non-profit). The intermediary partner provides an outlet for coordinating with community members.

Bardzell[25] asserts four concerns with PD in relation to power: (1) it has been diluted by some researchers to show they are using a user-centered approach just by having users participate in a design process yet still maintaining unilateral control over the design; (2) there are issues with who determines what participation means and what roles participants have in control, and what form of participation users participate in; (3) who controls what alternatives participants have to using other methods; and (4) how local accountability and community prioritization are manifested in design needs. These issues reflect a concern for researchers holding power in the PD process. Participants may also perceive their design contribution at varying levels depending on how useful they perceive their technical skills. Brough et al[63] explored participant's experiences in developing mobile technology through a power relations lens, power sharing in collaborative processes, and how participants perceived their abilities in graphic and technology design as useful. They suggest that PD occurs on a spectrum, one end being designer-led and the other being equal participant/designer involvement in all aspects of the design process[28]. Brough et al.[63] suggest an alternative perspective on participant perception of power in the design process. Stakeholders perceived their participation as less influential to the design outcome yet still expressed some semblance of control and ownership in the design process. While some may believe that the ideal for PD is for stakeholders to have direct participation at all levels, it is not always feasible. Participants may still hold a sense of empowerment even if they may

be unable to participate at every level of the process (i.e., limited ability or desire to learn how to do computer programming).

Not only do power dynamics come into play between researcher and participant, but influential undercurrents may also arise between community participants. There is potential for local leaders to dominate participation which may leave out “less privileged” community members or cause agreement bias for fear of leader retaliation[28, 61]. Drain et al.[28] noted that in PD sessions with Cambodian farmers, group leaders were seated at the front of the room which they believe may have signified inherent power structures in the group. They suggest a potential solution might be to use small groups to encourage discussion among “less privileged” voices in the PD session. Moreover, Hussain, Sanders & Steinert [58] recognize that power structures and customs for interacting with children may make it difficult for them to interact as equal design partners with adults. Special attention should be placed on how participants are grouped together in a workshop to ensure some voices are not overpowered. Grouping by specific criteria could also be considered rather than including a sampling of various users placed in a single group [58]. For example, having executive leadership and administrative assistants participate in a design workshop together may limit participation due to worker-supervisor power dynamics. Being flexible and adaptable to PD group methods based on local and cultural context is necessary.

To give more power to participants, some researchers have approached researcher-participant power dynamics through capacity building efforts for local community participants to lead their own PD efforts. Gooch et al[64] used community mobilizers who support local people to lead efforts to take action within their community. These community mobilizers had more knowledge about community norms and needs than the designers so were able to identify opportunities and challenges based on their existing relationships with community members. Drain et al.[28] included a capacity building step in their research with Cambodian farmers. It involved assessing participant capacity and experience to learn design, identifying sociocultural dynamics such as community priorities and local power dynamics. It also involved making design activities contextually relevant to the community and included flexibility for the community to disrupt the design process for local priorities.

In another study, Australian Indigenous student leaders were trained by designers to implement PD workshops in their community while designers took a supportive role[60]. To build trust with workshop participants and encourage open dialogue, student leaders used a storytelling approach in which they shared personal stories about themselves. Although capacity building does not factor in all dynamics of power, particularly local power structures between community stakeholders or community motivation or needs, it does attempt to equalize some aspects of control regarding design process knowledge so that community members are more equipped to lead design efforts.

Transparency & Accountability

Transparency and accountability help expose power dynamics in the PD process and facilitate collaborative relationships. Developing relationships over time helps with transparency by permitting all groups (e.g. researcher, participant, agency, community) to realize spoken and unspoken rules[57], community and partnership dynamics, recognizing resource availability and needs, establishing locally responsive timelines, and co-analyzing and establishing credibility of findings. It also should include involving the community in collaborating on what is meant by participation and interaction[56].

Broadly speaking, being transparent and accountable would ideally be achieved through regular interaction with community representatives to evaluate action towards community empowerment, democracy and equality[65]. However, the people who are selected to facilitate these design efforts matter substantially for these actions to be successful. To develop tools that are most salient to the intended users, organizational partners should recognize the value of community participation and have genuine interest in understanding community needs and norms. By having their support, they are more likely to be more receptive to PD activities. Organizations with a hierarchical structure may be less likely to be open to transferring decision-making power in design development to community participants[58]. Moreover, community organizations selected to represent the project may have hidden agendas or prioritize areas that do not reflect the community's needs or concerns[57].

This makes it important to also get to know the community beyond the local organization's lens by interacting with community members that are not affiliated with the partner organization. This involvement may occur well before PD activities take place and continue over time (during and after PD activity)[59]. It also helps to have local representatives employed on the research team as they are likely to have familiarity with community context that would be difficult to recognize otherwise. Not only does employing local community members on the research team help to understand community context, it also encourages PD research capacity in the community through developing participant experience with PD and research skills. Developing these skills may increase longevity of future PD activity in the community. In addition, time and resources could be allocated to train other community members on design methods[58, 60]. These capacity-building efforts provide more opportunities for community participants to become accountable for maintaining efforts towards continuing PD activity.

Challenges for Using Participatory Design with Native Communities

Many of the challenges to using PD highlighted above are also going to be prevalent for PD with Native communities. However, challenges will be dependent on which Native communities participate, the partnerships established, and the local context. Some potential challenges are provided below.

Distinctive cultural protocols: A major challenge for using PD with Native communities would be attempting to use a "one-size-fits-all" design approach for all communities. According to the Bureau of Indian Affairs, there are currently 578 federally recognized tribes in the United States and there are also other tribal communities that do not have federal recognition. Some of these communities have similar practices but there is great variation across tribal communities in cultural protocols and traditions. Moreover, urban communities include representation from many of those tribes which make it difficult to account for representation from each tribal community in urban areas.

Community oversight: Another challenge might be in determining which stakeholders in the community should be included in the PD process and to what extent. Health research efforts

typically have oversight from tribal health services and their own ethical review boards which also have wide variability. This means that local review entities may need to provide guidance and oversight into the study before, during and after it is complete. In some cases, these oversight committees may have expectations for a design that conflict with what participants in PD activities suggest.

Rural communities: Additional considerations will be needed for studies conducted in rural Native communities, particularly in Alaska, but not exclusively. For example, there may be limited access to technologies which may pose challenges for technology training and/or cost of supplying technologies. Travel to and from rural communities could be costly with limited availability of flights to some communities requiring extra costs for lodging.

Ownership and Native intellectual property: Many tribal communities and organizations have regulations in place that state that any data resulting from research conducted with their communities belongs to that community. Therefore, data sharing agreements may place restrictions on how PD data are used. Similarly, PD may result in the use of traditional Native knowledge in either the process of PD or the product. Considerations for protecting this intellectual property will need to be factored.

Noteworthy Limitations for Community-Engaged Approaches

Although a community-engaged research approach such as participatory design may be appropriate to utilize in Indigenous communities, there are also significant limitations to consider from a postcolonial perspective. Assuming that a community-engaged approach equates giving power to a community is problematic as the concept of empowerment varies across cultures and communities[46]. Community members may be impartial to research or have different priorities to address that may not be addressed through a proposed research study. Moreover, there may be challenges in determining which community members have the authority to speak for the rest of the community. In some cases, the agents chosen to represent the community may establish their own dominance and control reinforcing colonial power relations[46, 66]. In addition to deep-rooted epistemological concerns, there are also technical limitations. Community engagement is a slow process

requiring time to develop and maintain relationships which may present time limitations and financial constraints[11, 20, 67]. These restrictions are often unrealistic given funding agency expectations of timely progress for study outcomes, which do not often factor in relationship development or community collaboration[46]. Moreover, community priorities may shift and, if the research is no longer a community priority, then continued community engagement may falter[46].

Taking these limitations into consideration, I wanted to be sure to reflect on how to improve the research and design process. Chapters 6 and 7 provide more information about how I've incorporated community strengths and Indigenous research approaches to the research and design process.

Chapter 3 Summary & Contributions

This chapter examines the use of participatory design (PD) with historically excluded communities, focusing on its challenges, lessons learned, and applications in Indigenous contexts. PD is a user-centered approach that seeks to democratize design by involving stakeholders in meaningful ways. However, when working with marginalized communities, researchers must navigate issues such as power dynamics, trust-building, cultural protocols, and ethical considerations.

Key lessons include the importance of understanding community context, forming mutual trust, addressing power imbalances, and ensuring stakeholder decision-making and benefit. Challenges such as limited access to technology, rural logistics, and community oversight are highlighted, particularly in ANAI communities. I also emphasize the need for transparency, accountability, and capacity-building efforts to empower communities to lead their own PD initiatives.

While PD offers opportunities for collaboration, I acknowledge limitations, such as time constraints, funding pressures, and shifting community priorities. I advocate for culturally sensitive approaches that respect Indigenous knowledge systems and adapt to local

contexts. I underscore the importance of equitable partnerships and ethical practices in participatory design with marginalized communities.

The contributions of this chapter are:

1. **Advancing Participatory Design (PD) with Marginalized Communities**: I provide background into the challenges and lessons learned when using PD with historically excluded communities, emphasizing the importance of addressing power dynamics, trust-building, and cultural protocols.
2. **Contextualizing PD for Indigenous Communities**: I highlight some unique challenges of applying PD in ANAI communities, such as cultural diversity, rural logistics, community oversight, and intellectual property concerns, offering practical considerations for researchers.
3. **Promoting Ethical and Collaborative Research Practices**: I advocate for transparency, accountability, and capacity-building efforts to empower communities, ensuring equitable partnerships and mutual benefits in the design process.
4. **Integrating Postcolonial Theory**: I align PD with postcolonial theory, emphasizing the need to address historical power imbalances and prioritize Indigenous epistemologies and values in research and design.
5. **Highlighting Limitations of Community-Engaged Approaches**: I examine some assumptions of empowerment in community-engaged research, addressing challenges such as time constraints, funding pressures, and shifting community priorities.
6. **Practical Recommendations for Researchers**: I offer actionable strategies for improving PD processes, such as fostering trust, adapting methods to local contexts, and involving diverse stakeholders, including Elders and non-intended users.

Overall, this chapter contributes to advancing ethical, culturally sensitive, and inclusive research and design practices that prioritize the perspectives and needs of historically excluded communities.

Chapter 4: Technology to Support Collaborative Dissemination of Research with Alaska Native Communities

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Abstract

Marginalized communities often mistrust research due to a history of unethical practice and limited community engagement. Research community engagement is expected with Indigenous communities, but few empirical studies have explored engagement in results dissemination, let alone using technology. Studies on using technology to disseminate results focus on health and research professional audiences. This paper discusses Alaska Native stakeholder values on technology to facilitate collaborative results dissemination. In this formative study, six participants engaged in participatory design activities on collaborative results dissemination. Sketches and interviews were analyzed deductively using a value-based codebook. Study findings highlight the importance of community context and transparency. Contextual awareness includes understanding local culture and power dynamics, acknowledging the diversity of cultural practices within Alaska Native groups. Transparency is tied to clear communication: encouraging active dialogue and providing alternatives to communicate research. Technology that supports such collaborative dissemination could increase trust and improve adoption of research-recommended actions.

Introduction

Health research has impact when the people affected by health conditions can access and understand the research results, yet all too often, sharing coherent health research results with research participants and non-academic audiences is often neglected or done ineffectively[7]. For many researchers, the primary method of disseminating research results is to submit manuscripts to peer-reviewed journals or conference presentations which limits their audience to academic scholars [8, 10, 76, 77]. Limiting dialogue between non-academic community participants and researchers, many of whom may be unacquainted with community perceptions of health or community systems of sharing information, decreases the likelihood that study results will be implemented at a community level [10]. Collaboration between researchers and the communities that studies are conducted in can increase the likelihood that information is shared in more relevant community-centric ways. Studies suggest that research participants *want* to receive research results and propose that participants have a *right* to receive them for contributing

to the research [5, 6]. Other than using traditional academic dissemination methods (i.e. journal articles, conference presentations), limited progress has been made to ensure health research results are returned to participants or otherwise shared with non-academic community audiences [4].

These dissemination limitations can lead to the spread of misinformation and mistrust, which is especially problematic for communities facing extensive social determinants of health. American Indian & Alaska Native (ANAI) people have encountered innumerable research injustices, such as being exposed to procedures without informed consent [12, 78, 79] and having research results disseminated without community input or approval[14, 79]. For example, in the 1950's Alaska Native people were unethically recruited into a study that involved ingesting radioactive iodine (I-131) at excessive doses without adequate consent and without appropriate documentation for follow-up [79] which further motivates research mistrust. Oversights like these increase the need for transparency and accountability in research at all stages from project conceptualization to results dissemination. Moreover, ANAI people have been under-represented in national research initiatives—such as NIH's All of Us research program—or have not been consulted about how best to implement research or disseminate actionable findings relevant to community context[12-14]. Trust in health research influences trust in health services[79]. Marginalized communities, such as ANAI people, are less likely to trust the scientific community as a result of unethical research practices [80]. Egregious research violations have led to crucial research sovereignty in ANAI communities which has helped begin to mend their relationships with health research[12, 81].

In the past several decades, research in ANAI communities has become much more collaborative or community driven[46, 52, 82]. Despite this progress, only limited research has explored ANAI collaboration specific to results dissemination. Preliminary studies suggest that ANAI communities are interested in being engaged in the dissemination process[14, 83]. Previous research indicates that ANAI people want results that consider local context [84-86], appropriate language, information that is both practical to researchers and community members[76], and information that considers ANAI values, knowledge, and

expertise[86, 87]. A collaborative approach to dissemination has potential to strengthen ANAI trust in research and enhance researchers' awareness of community concerns and perceptions of research[14, 86, 88]. Recently, ANAI -led organizations have seen success in informing ANAI communities about the risks and benefits of the COVID-19 vaccine. For example, the Urban Indian Health Institute conducted a US national survey with 1,435 ANAI respondents on community perspectives of the Covid-19 vaccine[89]. Data from this survey have been used by the Urban Indian Health Institute and other ANAI serving organizations to develop social media campaigns and educational material about COVID-19 and vaccinations. A key finding from this survey reinforced the importance placed on community with 74% of respondents sharing a responsibility to their communities for getting vaccinated[89]. This information has helped tailor COVID-19 prevention and education materials to community vs. individual benefit. Despite advances, limited empirical evidence is available about values ANAI stakeholders place on technology-facilitated collaborative dissemination let alone what they would want these technology tools to include. Further dialogue could encourage multi-directional learning and enhance partnerships leading to improved communication and trust in research promoting more participation in research where ANAI representation is now limited. New methods and technologies for respectful and culturally responsive research results dissemination are urgently needed both to help researchers engage diverse participants and to serve these communities better.

Internet-based technologies (i.e. social media, podcasts, websites, and mobile applications) have become more interactive and consumer-centered allowing for engagement and control over content that users interact with [68]. These technologies increase the potential for conveying health-related research results to a broader audience. Moreover, these technologies have democratized access to research information, giving users the flexibility to manipulate how they see and share information [68] including health research results. Bernhardt, Mays & Kreuter [68] have coined the term "Dissemination 2.0" to represent the use of cooperative internet-based technologies to disseminate research products (e.g. results, educational content) claiming that it "represents an interactive approach of exchanging scientific evidence among collaborative members of a research-to-

practice network that leverages their user-generated knowledge and harnesses their collective intelligence for increased effort and continuous improvement...[and] takes advantage of the core foundations of Web 2.0 applications—collaboration, participation, multidirectional information exchange—to improve current dissemination activities and advance the translation of research to practice"[68]. This approach leverages relationships with healthcare practitioners, rather than average community members, but the core foundations of collaboration, participation, and multidirectional information exchange are potentially valuable for a wide range of communities. Preliminary studies on the use of internet-based and mobile technologies indicate a need to further explore these modes of research dissemination, particularly to community audiences.

Social media is recommended as a possible tool to broadly disseminate research results. Most studies investigating using internet-technologies to disseminate research results have focused on sharing results with academic and healthcare provider communities. Many have only reported web analytic data on website and social media reach, indicating increased access to their research content but did not provide much context about the user or their experiences [69-71]. One study conducted with Australian, Indonesian, and Malaysian researchers asked about their social media research dissemination practices. Only 15% (n=128/852) of the survey respondents reported using social media to share research results [72]. In one web analytic study, Twitter was the most active platform for disseminating research articles; however, it is unclear whether these research articles were shared outside of academic networks or how tweeting them might impact science practice [70]. Still, another survey conducted with clinical trial research participants suggested letters or fliers distributed via email and study website postings as most desirable, while Twitter, text messages, and conference calls were least desirable [73]. It may be that using Twitter to share research results is more accessible to academic communities than it is for research participants.

Internet-based technologies have also been used to engage research-related dialogue between a research center and other researchers and community stakeholders. Soto et al. [74] used Twitter to promote online community-engaged research training curriculum to

both researchers and community members. Only 10% (n=19) of the trainees were community members. While the researchers suggest social media-based community engagement is promising, there were important study limitations. Particularly, their inability to study demographic characteristics, including a user's status as a community member vs. a researcher, means more research is needed to understand who the users of these strategies include [74]. Feasibility studies on linking podcasts via social media (e.g. Twitter, Facebook) have also been explored as a novel form of communicating health research and facilitating engagement and dialogue [71, 75]. In one case, dialogue occurred through user comments and researcher replies on social media posts that linked research podcast recordings [71]. As the study only examined web analytics and comments made on social media posts, the results of the study were limited to the comments made to the posts, and web analytics such as internet shares, and number and duration of podcast plays. The authors suggest future studies are needed to explore how effective the podcasts were for reaching audiences, acquiring knowledge, and successfully communicating health topics content [71].

This formative study explores health researcher and Alaska Native community stakeholder perspectives on technology-facilitated collaboration in the dissemination of health research results. Participants were engaged in a design process to develop low fidelity prototypes for community-researcher collaborative dissemination. This paper discusses participant preferences and values with respect to using technology to facilitate collaborative results dissemination.

Researcher Stance

Ms. Dirks positions herself as a mixed-heritage Alaska Native/White community-engaged researcher with community roots in an Alaska Native village in the Aleutian Islands. As an Alaska Native researcher, she has had experience being both a health and social sciences researcher as well as a community participant in health and social research studies. A significant amount of her research experience has been with Tribal communities in Alaska and elsewhere on topics relevant to community mental health and wellbeing. This dual role

as a health services researcher and an Alaska Native person motivates her work and gives her unique perspective on both sides of the relationship between community and research.

Methods

This formative study was approved by the University of Washington Institutional Review Board. This study was conducted to develop a better understanding of: (1) stakeholder-defined risks and benefits in using technology to collaborate on health research results dissemination; and (2) stakeholder values related to collaborative research results dissemination.

This exploration was framed using components of a value sensitive design (VSD) theoretical approach. VSD is an adaptable approach that engages moral and ethical considerations for technology design while also leaving room to explore other value considerations important to system stakeholders [24]. It holds an "interactional position" which places attention on how people's values determine how they interact with a technology even if it wasn't designed for the explicit ways it is being used [24]. It is an iterative process holistically integrating conceptual, empirical and technical aspects [24]. This study involves the formative stages of a conceptual and empirical investigation of values relevant to community-researcher collaborative dissemination. Interest at this initial stage is to examine how well the conceptual value components compiled from the existing Indigenous community-engaged dissemination research literature align with the data contained in the participatory design [90] activity artifacts created in this study. It is our intention to use data from this formative study to improve upon and iterate a value-based conceptual framework for collaborative dissemination considering an Alaska Native context.

Conceptual Investigation Methods

Reflecting on the flexibility of VSD, prior to empirical data collection, a literature review on researcher-community collaborative dissemination in Indigenous communities was conducted to create a list of value-based themes related to the design artifact data that were collected for this study (Table 1). These values were examined in relation to the design

artifacts created during participatory design activities (See Figures 1 & 2 for example sketches).

Empirical Investigation Methods

A participatory design approach [90] was used consisting of: (1) a list making activity in which participants were asked to write out a list of risks and benefits for using technology for Alaska Native community and researcher dissemination collaboration, (2) creation of a prototype sketch of the technology-based tool considering their ideas from the list-making activity; and, (3) scenario development which involved drawing or orating a story in which their prototype might be used. Using a deductive value-oriented coding manual [91, 92], data obtained from sketches and accompanying scenarios created by participants were analyzed. The coding manual was created using conceptual definitions informed by existing literature. The literature that was used to inform definitions was isolated to community-engaged and collaborative dissemination-related health research specific to Indigenous communities. Table 1 provides a list of these value-based conceptual definitions for collaborative dissemination.

Table 1. Conceptual value definitions and themes – Native research results dissemination conceptual framework

Value	Definition	Literature	Themes

Partnership	Arrangement where partners (community & researchers) agree to cooperate to advance their mutual interests.	Blue Bird Jernigan et al., 2018[52]	• Power dynamics
			  ○ Internal (with community) & external (researcher-community)
			• Individual vs. collective sense of community
			  ○ Threat of technology on collectivism

Context	Considers the historical, physical, and social realities of the community in relation to the research study and research conducted in Native communities in general.	Legaspi & Orr, 2007;[86] McDonald et al., 2016;[84] Timmons et al., 2007 [85]	• Epistemological nuance
			  ○ Native ways of knowing differentiated from Western & Alaska Native cultural groups
			• Geography
			  ○ Rural geographic isolation
			• Pros and cons of technology use
			  ○ Offer alternatives for in-person communication (pro)
			  ○ Limited access to broadband (con)

Transparency	Conducting research in a way that it is easy for others to see what actions are performed. Transparency implies openness, communication, and accountability.	Bowen & Martens, 2005;[93] Elsabbagh et al., 2014 [94]	• Facilitates clear ongoing communication • Need technology skills to fully benefit • Limit technical jargon • Access guidelines & restrictions

Dialogue	Considers the community as experts in their physical, social, and spiritual environment and meaningfully incorporates this knowledge in the results dissemination process.	Rivkin et al., 2013 [87]	• Mixed modes of communication
			  ○ Text, audio, video, etc.
			• Synchronous/Asynchronous
			  ○ Time for reflection (sometimes days in between needed)
			• Mutual educational benefit
			  ○ Researchers learn from community & community learn from researchers

Data Collection Process

A purposive sampling strategy[95] consisting of email and word of mouth was used to recruit participants with strong connections to an urban Alaskan community. Participants were selected based on our prior knowledge of them having experience either being a health research participant or a health researcher. Inclusion criteria required participants to be 18 years or older and interested in exploring health research results dissemination processes

in Alaska Native communities. Recruitment and data collection took place in May 2019 and early March 2020. Participants provided verbal consent. Design sessions were audio-recorded and transcribed, and extensive notes were taken throughout the process. All data collection took place in each individual participants' private home. Participatory design sessions ranged from 30-60 minutes.

Participants

Six participants engaged with us during one of two time periods (May 2019 & March 2020). For the four who participated in May 2019, three self-identified as women, one as a man. Three self-identified as Alaska Native and one was White. One was a health researcher and the remaining three were Alaska Native community members living in an urban Alaskan community. For the two who participated in March 2020, one self-identified as a man and one as a woman. One identified as a non-Native health researcher with experience in Alaska and other American Indian communities. The other participant identified as an Alaska Native community member living in Seattle with roots in a rural Alaskan community. Participant ages ranged from 37-68 years old. All participants had some experience in being research participants in previous health-related studies on topics in physical and behavioral health.

Findings

The lead author (Ms. Dirks) conducted a deductive analysis of session transcripts and written text on participatory design sketches and scenarios using a deductive value-oriented codebook[92] consisting of the conceptual values noted in Table 1. Themes are highlighted below by these literature-informed conceptual values (partnerships, context, transparency, and dialogue). To distinguish between community and researcher participants, community participants are identified with the prefix "C" and researcher participants are prefixed with "D".

Partnerships

Power dynamics

Partnerships could benefit from awareness of power dynamics and engaging with various stakeholder groups in the community, not just those in a power position. This engagement should occur over time as a developing process, rather than as a product. Research results dissemination is often viewed as a product (i.e. manuscript, presentation). This limits its longevity. Seeing research as a process of ongoing communication has impacts on partnership. Participants recommended youth as a community sector to involve in collaborative partnerships. Community participant C4 suggested that young people are often left out of decisions that have potential direct effects on them; they are often placed in a subordinate position to adults. Researcher participant R1 indicated that since young people will potentially be impacted by research in the long-term, they should be present to share perspectives about what problems they want to solve and what technologies they would want to interact with.

Individual vs. collective sense of community

Technology may pose possible threats to Alaska Native community norms of collectivism. A dissemination system has potential to cause isolation and individuation. Community participant C3 highlights this concern: “How did it work in the past for everyone to work together for communities to help sustain themselves? If it becomes more individualistic there is a breakdown. When does functional become dysfunctional? Would technology encourage the [individual] *me-me-me* attitude that was once [traditionally the Native collective] *we-we-we*?”.

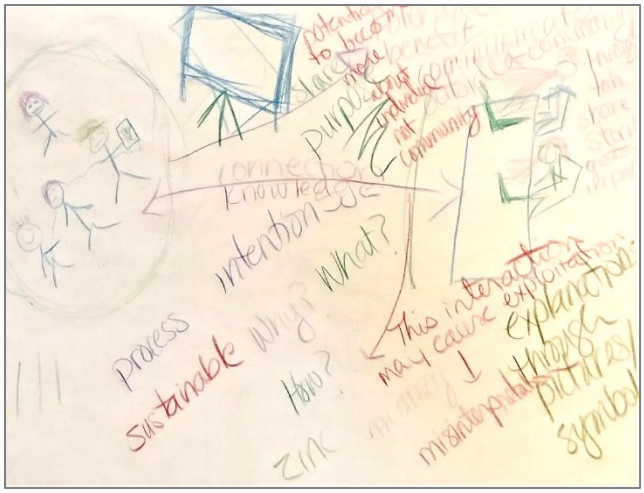


Figure 1. Participant Example 1 Stakeholder Scenario Sketch.

Context

Epistemological nuance

The perception of Alaska Native communities' epistemology is an important concept related to community values. Community participant C5 suggested that "[m]aybe sometimes Native people seem to be so indecisive because they are considering other parts of the community [in their decision making]. There is [a perception from outsiders that there is] no motivation to try to make things better". This represents a tension between collectivist worldviews such as those found in many Indigenous communities in contrast to individualistic worldviews such as those most prevalent in mainstream United States communities. For this participant, misperceptions on decision-making processes can cause conflict if community context is misunderstood. Researcher participant R2 also stressed that each community has its own unique characteristics, especially within Alaska Native communities and stated that "sometimes we [Alaska Native people] are grouped as one culture when we have so many cultural beliefs that vary even within our people".

Geography

Geographic placement also has contextual importance. Rural Alaska Native communities are often difficult to get to. Transportation to and from communities becomes an important context value to consider. Some communities rely on air travel to get to and from their home location. This limits resources and opportunities for in-person collaboration due to

constraints related to weather and airfare costs. Technology can be a benefit to communicating with people at a distance where costs of travel can range in the thousands of dollars for airfare alone. However, such an approach may also pose a problem for those communities that still have limited access to technology both peripheral and via infrastructure.

Transparency

Participants shared views on technology as both a facilitator and barrier to collaboration. C3 stressed importance for clear ongoing communication even before research results are ready to be presented. They viewed technology (i.e. websites) as a way for community members and researchers to maintain active communication. At the same time, C3 also viewed constraints of technology for transparency. For example, community members who have limited technology skills (e.g. Tribal Elders), may feel excluded from optimal collaboration making technology training or local facilitation an important consideration. Furthermore, transparency also includes using language and defining unfamiliar terms or norms, as stated by both researchers and community members. Researchers should limit technical research jargon and community members should define local terms and contextual factors that researchers may misinterpret. Community participants (C3, C5) also illustrated potential for mistrust in using technology to collaborate. They placed value on having guidelines on who has access, what it would be used for, and when people would have access.

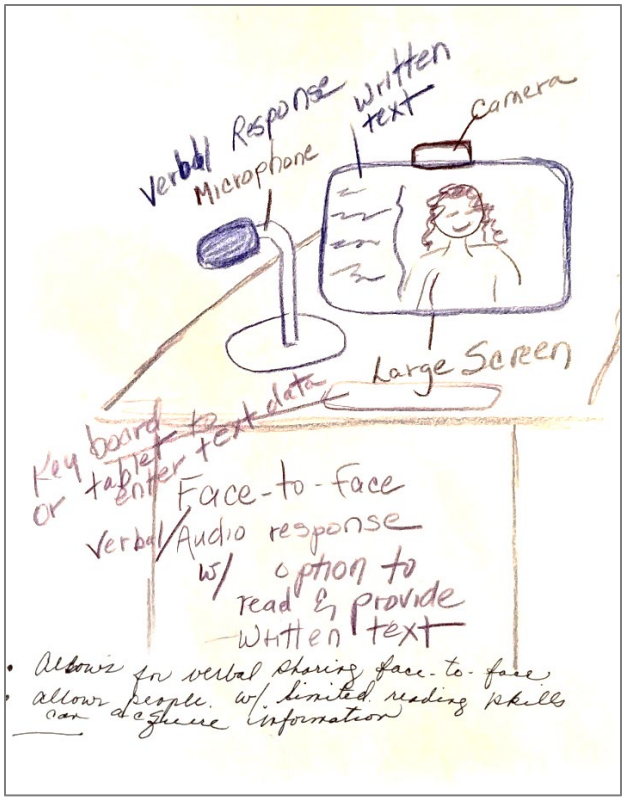


Figure 2. Participant Example 2 Stakeholder Scenario Sketch.

Dialogue

Participants discussed the benefits of technology for facilitating dialogue. To some participants, this dialogue does not need to be bi-directional oral communication but may benefit from having mixed modes of communication, such as the combined use of text, video, and audio. Researcher participant R4 discussed how dialog may benefit from being both synchronous and asynchronous. In their scenario, community participants would meet as a local group independently to review non-technical research results that researchers would have shared with them before meeting in person. They stated that, in many Alaska Native communities, people need time to reflect before having discussion. A live video conference could occur after the community group had time to reflect and deliberate on their own. This video conference would be an opportunity for the community to ask researchers questions and share their response to the results and for researchers to orally articulate results and ask the community questions. The idea of mutual educational opportunities was also something to consider regarding dialogue. For example, researchers

may learn from Alaska Native people about local knowledge, processes and interpretations, Alaska Native community members may learn more about science and research from the researchers. This organic communication is less likely to occur if a manuscript were the primary form of dissemination. Additionally, one community participant (C3) suggested that in-person communication would be ideal yet would prefer a technological interface for dissemination to reading a peer-reviewed article.

Implications for Technology Design

Empathy and sincerity towards the values of the communities that we design with help us create technological systems that are likely to be more salient to their intended needs. Values can be difficult to isolate and often overlap and form networks showing interconnectedness. Co-designing with marginalized community participants can help expose values and how they are interrelated which can help equalize power dynamics between researcher and community member as well as expose community-level power dynamics that can unintentionally impact design. By being actively involved in technology design, community participants can highlight design flaws or features that do not align well with community collective norms. Active community participation can benefit design projects by having internal members of the community who understand cultural and epistemic nuances that may otherwise be missed by researchers with less familiarity with respective community context. As was discussed by one of our community participants, Alaska Native people have diverse cultural and linguistic backgrounds which make using a one-size-fits-all approach to participatory design for all communities a major challenge. According to the Bureau of Indian Affairs, there are presently 578 federally recognized tribes in the United States[53] and many other tribal communities do not have federal recognition. Some of these communities have similar norms and practices but there is great variation across tribal communities in cultural protocols and traditions. Additionally, urban communities include representation from many of those tribes which makes it difficult to account for representation from each tribal community in those settings. Moreover, local participation and design facilitation, particularly in rural isolated communities, can benefit

design by having support "on-the-ground" should travel or access to technologies become prevalent.

As with any participatory activity, it is important to understand the contextual nuances of conducting participatory design with a marginalized community, especially if the researcher is not already affiliated with the community. Although technology can support collaboration, it can also create barriers to collaboration that may not be exposed without understanding community norms. In our study, Alaska Native Elders or other community members with limited technology skills may have an opposite reaction to collaboration and instead feel isolated rather than more involved. An essential step to reveal these contextual distinctions is to spend time developing relationships with stakeholders and getting to know the community before initiating design activity. A proactive approach involving careful contextual analysis of the community, discovering potential problems, and developing and implementing strategies to address those challenges prior to starting design activities[57]. Awareness of context also includes understanding local culture, including how to approach participants and show respect in culturally-specific ways which can be achieved by spending time with different stakeholder groups, many of whom may not be the design's intended end user [58]. Furthermore, developing relationships before design activities may also help uncover hidden agendas that may conflict with participatory activities [57].

To support partnership, context, transparency, and dialogue, co-design methods incorporated with Indigenous epistemological approaches will be added to our future research activities to promote more community power to the design process. For example, design processes could include a digital storytelling component that integrates oral traditions with technology design and research. Digital storytelling involves a process of creating short, personal stories that are told through a recorded, first-person voiceover, still and/or moving images, and music or sound[96, 97]. Digital storytelling connects and supports people in natural ways and is in alignment with ANAI cultural practices that promote values through sharing stories. Using narrative methods such as digital storytelling help deconstruct power dynamics between researchers and community members and are also respectful of rich oral histories and cultural practices in ANAI and other Indigenous

communities[96]. Integrating these approaches will also contribute to the community-engaged research approach by adding to the body of knowledge on engagement in community results dissemination. Moreover, exploring research results dissemination from an Indigenous knowledge systems framework adds advantages to developing a culturally congruent conceptual framework that will increase sanguinity in health researchers' communication with ANAI populations. This integration has the potential to generate innovative culturally responsive user-centered design methods that may be advantageous for participatory design activities with ANAI and similar communities with robust narrative values. The digital storytelling method will provide participants' control over what they choose to share and how it is represented. Engaging participants in this way may increase parity by supporting their role as educators and owners of the knowledge they choose to share.

Conclusion

Conventional health research results dissemination approaches have often constrained marginalized communities' research engagement. Creating interactive systems that enable community-researcher collaboration may benefit Alaska Native and other marginalized communities by encouraging active communication that is germane to their respective communities. Study findings highlight the importance of community norms and context in developing interactive dissemination systems for collaboration with Alaska Native communities. Awareness of context includes understanding local culture, including how to approach participants and show respect in culturally specific ways. We need to pay attention to power dynamics and dedicate time with different stakeholder groups, many of whom may not be the design's intended end user. We also need to emphasize transparency with clear communication that promotes more active dialogue, potentially providing a variety of ways to communicate that would not otherwise be possible (i.e., mixed digital and analog media).

The findings from this study will be used to improve upon and iterate a value-based conceptual framework for technology-facilitated collaborative dissemination considering

ANAI community contexts. The results of this and our future planned research will benefit improved communication and trust in health research in ANAI communities. Such increased trust will in turn improve the impact of health research and health services by ensuring that outcomes of research are more effectively disseminated to ANAI communities. It will support communities in understanding the research and contextual community-level relevance, potentially incorporating research recommendations and support for technology adoption. Such collaborative efforts could also encourage increased participation in national research programs by increasing marginalized groups' trust in research. Similarly, this research builds connections between informatics researchers and ANAI communities urging further user-centered design collaborations. The conceptual framework, methodologies, and technology prototypes resulting from this and our planned future research could influence other historically marginalized communities by increasing their trust in and uptake of research results.

Acknowledgements

We would like to recognize the University of Washington GO-MAP fellowship program for the graduate funding support provided to Ms. Dirks during this project. We would also like to acknowledge the Alaska Native community members and health researchers who provided insight into the participatory design activities for this project. Professors Batya Friedman and David Hendry provided advice on VSD methodological approaches to use for this study and in future related research endeavors. Finally, we would like to acknowledge the iMed research group for their thoughtful discussions which prompted ideas on a previous research presentation of this formative study.

Addendum (This section has not previously been published)

As a follow-up to the above study, I collected additional data from ANAI community participants and ANAI health services researchers. This addendum provides a summary of

this study activity, including an updated value-based conceptual framework that was informed by data collected for the study described in this addendum.

To guide the development of design materials for future co-design activities and update the value-based conceptual framework developed above, I used value-sensitive design to explore stakeholders' values for community research collaboration in general and, more specifically, related to health research results dissemination. For this study, research questions included: "*What values do stakeholders hold for collaborative results dissemination? Results dissemination, more broadly? Using technology for collaborative results dissemination?*".

Methods

Data Collection

I conducted 3 futures workshops with ANAI stakeholder groups. The futures workshop model[76, 86] involves four phases*:*

1. Preparation: setting up data collection supplies and introducing the workshop guidelines to participants.
2. Critique*:* stakeholders critically explore the problem of results dissemination.
3. Fantasy: stakeholders generate creative ideas visioning the possible futures to improve research dissemination.
4. Implementation: stakeholder ideas are reviewed and evaluated on practicality to generate possible solutions.

During the critique phase, I shared several scenarios of different types of health research projects (e.g., behavioral health, precision medicine, chronic physical health condition) with workshop participants. In addition to asking participants generally about results dissemination, I also explored the values and value tensions stakeholders perceive on the use of technology to engage stakeholders in research collaboration. Workshops were photographed (removing images of participant identity), audio-recorded, and transcribed with informed consent from participants. Workshops took approximately 90-120 minutes.

Data Analysis

I used Dedoose to code transcript data for themes to explore adaptations to the existing conceptual framework – partnership, context, transparency, dialogue.

Participant Characteristics

Both ANAI community members and health researchers participated in workshops. Community member workshops and health researcher workshops were conducted separately from one another. Seventeen participants provided feedback during the workshops:14 community participants and 3 health researchers. Ten participants self-identified as women, and 7 as men. All participants are Alaska Native and all but 2 had some experience being research participants in previous health-related studies on topics in physical, environmental, and behavioral health.

Findings

Futures workshops explored the following concepts: problems with research results dissemination, improvements for research results dissemination, and ANAI wisdom and values. A summary of each of these topics is provided in this section below.

Problems with Results Dissemination

ANAI community participants expressed concerns regarding the sharing of health research results with the Alaska Native community. Common themes emerged, including a lack of offer and follow-up for receiving results, limited accessibility of shared information, language barriers with technical jargon, and the impact of generational trauma from unethical research practices, perpetuating research mistrust. Additionally, participants felt that their perspectives were not sought by researchers, which extended to the sharing of results, where discrepancies in data were reported, and Alaska Native knowledge was often disregarded. These issues collectively contribute to a continued sense of mistrust in research result sharing within the ANAI community participants.

Researcher participants identified several issues specific to their role in disseminating research results. These included limitations and prioritization of traditional academic

means of dissemination, a mismatch in excitement levels compared to community members, and challenges related to translational research and communication. They also expressed concerns about the misuse of disseminated results and emphasized the importance of providing contextual information. Addressing these challenges can lead to improved dissemination strategies and better research engagement with the ANAI community.

Participants expressed concerns about using technology to share research results. They emphasized the importance of confidentiality, particularly in distinguishing between individual and summarized results, and the potential risks of hacking. Intellectual property of Indigenous knowledge was also highlighted, noting the need to protect certain cultural information dependent on the community and topic. Access issues were raised, including a potential for limited technology proficiency among Elders and constraints in accessing newer technology devices or in having sufficient bandwidth to access multimedia information. These concerns underscore the necessity for secure and respectful technological approaches that address access barriers when sharing research results with the ANAI community.

Improvements for Results Dissemination

Participants shared valuable insights on how their communities share wisdom and knowledge, highlighting hands-on learning from direct experiences and the crucial role of Elders in transmitting knowledge. They emphasized the importance of mutual benefit between Elders and Youth, where Youth teach Elders technology while Elders pass on cultural teachings. Wide sharing of research results was seen as essential, extending beyond research participants and leaders to include the entire community. Storytelling emerged as a powerful method to convey knowledge about the world, teach moral lessons, and preserve community history and relationships.

Participants offered ideas for enhancing the sharing of health research results with Alaska Native communities. Suggestions included diverse dissemination methods like face-to-face engagement, word-of-mouth communication, newsletters, text messages, and audio-visual

tools. They emphasized the importance of researcher training in cultural understanding and translational research methods. Community involvement was highlighted through member-checking, collaboration with trusted individuals, and engaging various age groups to foster trust and understanding across generations. These recommendations prioritize accessibility, cultural sensitivity, and community engagement in sharing research results.

Native Wisdom and Values

I asked participants to share with me ways that their communities share wisdom and knowledge and how these forms of sharing can be useful to research results dissemination and communication.

Participants shared that wisdom can be passed on through hands on learning from experiencing things through doing them. Many talked about the importance of Elders in the community passing on knowledge through doing and showing. In one workshop there was an interesting discussion on elder-youth mutual benefit. For example, having Youth teach Elders how to use technology in exchange for Elders teaching Youth about their culture. One participant highlighted this concept with "*I'll help you, you help me. I teach you to check your email. You teach me to weave a basket or teach me to hunt*".

Participants also shared about values for sharing widely, not just with those who participated in research or those in leadership positions. Research results should be shared with everyone. Another common value brought up was the importance of storytelling to share wisdom. Participants talked about how storytelling shares knowledge about the world around them and lessons about morality, history, and relationships.

Updated Conceptual Framework

In considering these additional data, I updated the conceptual framework (*See Figure 3*). In this updated model, the four original concepts of Context, Dialogue, Transparency, and Partnership remain. But, based on data from this expanded study, two of the original concepts were updated—*Dialogue* was expanded more specifically to include *Communication*, and *Partnership* was expanded to also include *Collaboration*. Participants expect not only to be able to have a dialogue about research but also want more

communication, regardless of it being a dialogue. Participants also reinforced the importance of community partnership in research dissemination but shared that this partnership requires active meaningful collaboration. The concepts of *Native wisdom and values* reverberated throughout this study, so within the updated model, each of the 4 preliminary concepts are overlayed by Native Wisdom. Thinking of this metaphorically, using ANAI skin beadwork, one might consider Native wisdom and values as a deer or moose hide, with the four concepts (partnership/collaboration, context, transparency, and dialogue/communication) the beads. The hide supports the added beads just as Native wisdom supports the concepts and makes them stronger.

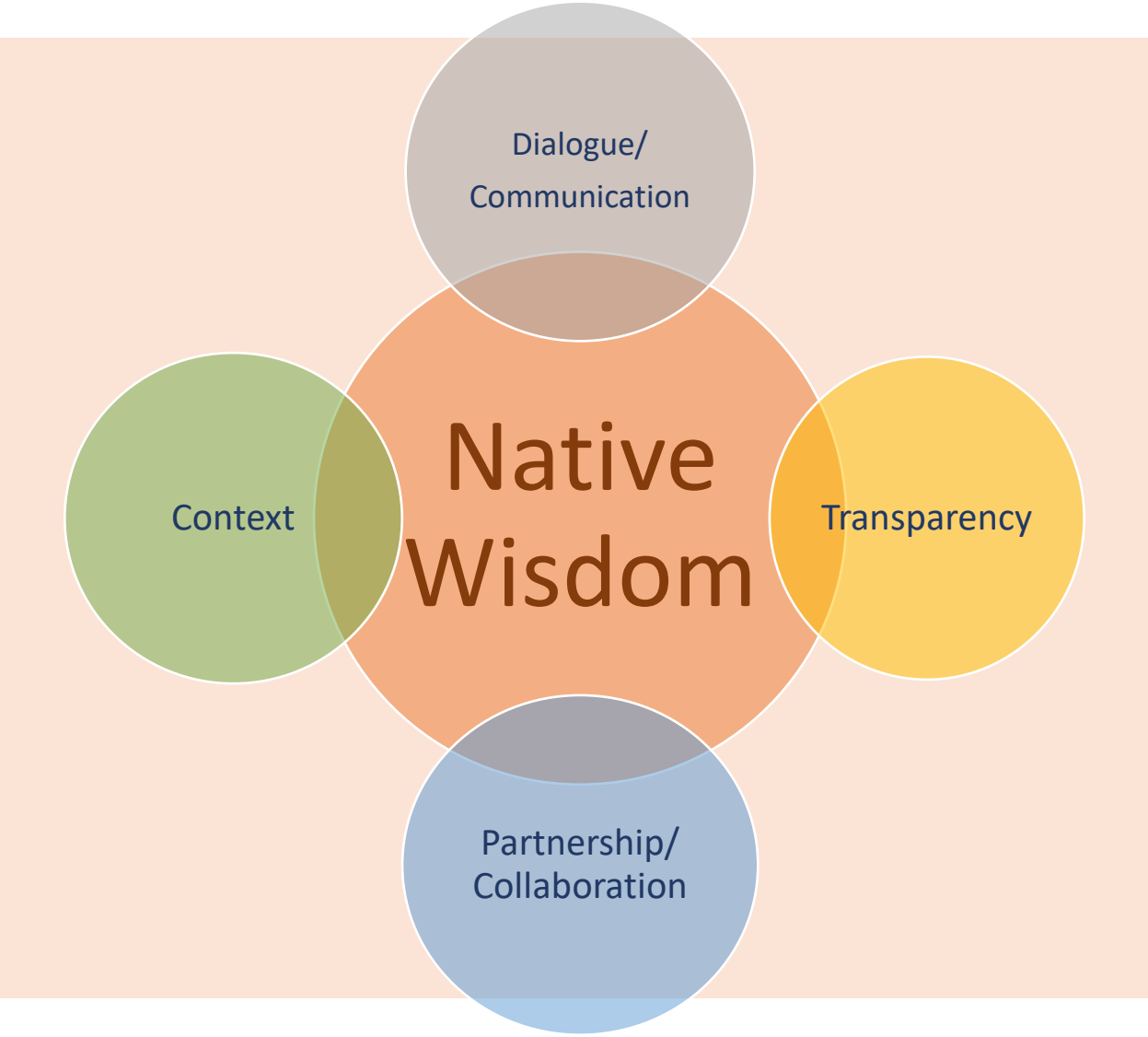


Figure 3. Updated Conceptual Framework

Chapter 4 Summary & Contributions

This chapter explores the use of technology to support collaborative dissemination of health research results with Alaska Native communities. It addresses the mistrust marginalized communities often have toward research due to unethical practices and limited engagement. In study Aim 1, I focus on Alaska Native stakeholder values, emphasizing the importance of partnership, community context, transparency, and dialogue in research dissemination. Using participatory design methods, six participants provided insights into risks, benefits, and preferences for technology-based tools to facilitate research collaboration. Key findings highlight the need for culturally responsive approaches that respect local norms, power dynamics, and diverse communication methods. I advocate for co-designing technology systems that integrate Indigenous epistemologies, such as digital storytelling, to enhance trust, communication, and adoption of research outcomes. I also developed a preliminary value-based conceptual framework for ANAI health research results dissemination. Findings from futures workshop data collection with an additional 14 ANAI participants informed an updated conceptual framework emphasizing partnership/collaboration, context, transparency, and dialogue/communication, all underpinned by Native wisdom and values. Ultimately, the study seeks to improve health research dissemination practices and to foster stronger partnerships between researchers and Alaska Native communities.

The chapter contributes the following:

1. **Highlighting Stakeholder Values**: I identify key values—partnership, context, transparency, and dialogue—that ANAI stakeholders prioritize in collaborative research dissemination.
2. **Contextual Awareness**: I underscore the need to consider ANAI epistemologies, cultural diversity, and geographic challenges, such as rural isolation and limited access to technology.
3. **Transparency in Communication**: I stress the importance of clear, jargon-free communication and guidelines for technology use to build trust and ensure inclusivity, especially for community members with limited technology skills.

4. **Technology Design Implications**: I propose integrating Indigenous epistemologies into technology design to align with cultural practices and support deconstructing power dynamics.
5. **Framework Development**: I share a value-based conceptual framework for technology-facilitated collaborative dissemination tailored to ANAI contexts.
6. **Updated Conceptual Framework**: Based on expanded data from futures workshops, I share a refined conceptual framework to include communication and collaboration, overlayed by ANAI wisdom and values reinforcing the importance of meaningful engagement and dialogue that values the strengths of ANAI worldviews and values.

These contributions provide insights into designing culturally responsive and inclusive systems for disseminating health research results, which can benefit ANAI and other marginalized communities.

Chapter 5: Using Co-Design Data to Develop a Prototype for Alaska Native Health Research Results Dissemination and Communication

This chapter has not previously been published

Introduction

In this chapter I provide information about the process of using co-design workshop data to develop a low-fidelity prototype grounded in data collected from workshop participants. For this study, the research question was "*What aspects should be included in a prototype for collaborative health research results dissemination for ANAI communities?*"

Methods

In this section I share more about the methods used for my Aim 2 co-design study, including the design method, analytic method, prototype development, and participant characteristics.

Design Method

I conducted a three-session series of four co-design workshops with ANAI community participants. The purpose of the workshop series was to co-design tools for community collaboration in the health research dissemination process. The series included three sessions that occurred within a one-week period. Session 1 (1.5 hours long) introduced participants to background and concepts of health research results dissemination, storytelling, and co-design. Session 2 (2.5 hours long) delved deeper into the co-design process and involved activities to co-design tools for ANAI people to collaborate with health researchers to share research results with ANAI communities. In session 3 (2 hours long), participants then used design ideas from previous sessions in this series to co-design a prototype for ANAI health research results dissemination.

Prototype Development

The process of developing the prototype involved several key steps. I worked with a research assistant (Victoria BearBow) to analyze workshop data and develop the prototype. First, we reviewed the thematic analysis of the co-design workshop data. This review helped us identify key insights, user needs, pain points, and design preferences highlighted by the participants. Next, we looked for recurring themes, patterns, and commonalities in the workshop data, grouping similar ideas and feedback together to gain a clear understanding of the most important aspects that needed to be addressed in the prototype. Based on the insights gained from the inductive analysis, we refined the objectives of the prototype, determining the specific aspects of the design and user experience to focus on. We then sketched out rough ideas for the prototype and created a user flow to map out the user journey. This visualization helped identify potential missing or unclear steps in the design. Using paper prototyping, we quickly iterated on different design ideas by creating simple wireframes of the user interface and arranging them to simulate user interactions. We then finalized the paper prototype and prepared it for user-testing and evaluation.

Analytic Method

We used inductive thematic analysis [152] to explore co-design session data for themes around prototype usability, functionality, context, and visual elements. Our analytic approach involved developing a coding scheme to systematically categorize and interpret the co-design data. The coding scheme included key prototype design categories which are presented below in *Findings*. By systematically coding the data using this coding scheme, we were able to identify and analyze the key themes and insights that informed the development of the prototype.

Participant Characteristics

Participants in this study represent a historically underserved and understudied population, particularly within the HCI and design field. Alaska Native communities (229 federally recognized Tribes) are composed of multiple, diverse, smaller groups of individuals who

may have relocated to urban settings from a variety of rural, geographically, and environmentally diverse regions across Alaska and the continental United States. Participants in this study do not represent all Alaska Native cultural heritage perspectives but provide a glimpse.

I collected data from December 2023 to February 2024 from participants residing in Anchorage, Alaska during the time of data collection. I recruited participants at a recruitment table set up in the main lobby of Southcentral Foundation's Anchorage Native Primary Care Center, a healthcare facility for American Indian and Alaska Native people. They were given information about the study and activities involved in the design workshops, including the expectation that they would attend all design sessions. Later, I contacted them by phone and/or email to schedule workshop participation.

A total of 12 Alaska Native community members participated in the design workshops. Participant Tribal heritage was diverse, including participants who self-identified, to the workshop facilitator, as Inupiaq, Athabascan, Tlingit, Aleut, and Yupik. Most self-identified as women (75%, n=9). Their age range was 25-86 years old with an average age of 55. All but one participant had prior experience as a participant in at least one health research study. Participants were assigned unique identifiers based on nouns (e.g., cat, snow machine, etc.) that they selected during data collection for anonymity and will be referenced as such in the findings.

Table 2 – Participant characteristics (N=12)

Participant	# Workshops Attended (out of 3)	Gender	Heritage	Age	Education	Setting where most time spent in Alaska	Research participation experience
Jellyfish	3	Woman	American Indian or Alaska Native, White	35	Training or technical education	City (e.g., Anchorage)	Yes
Hamster	3	Woman	American Indian or Alaska Native, White	27	Training or technical education	City (e.g., Anchorage)	Yes
Raven	3	Woman	American Indian or Alaska Native	55	High school diploma	Village (e.g., Kivalina	Yes
Orca	3	Woman	American Indian or Alaska Native	60	High school diploma	City (e.g., Anchorage)	Yes

Polar bear	3	Woman	American Indian or Alaska Native, Mexican	59	High school diploma	City (e.g., Anchorage)	Yes
Cat	3	Woman	American Indian or Alaska Native	25	Bachelor's degree	City (e.g., Anchorage), Small town (e.g., Wasilla)	Yes, as researcher
Ivory	2	Man	American Indian or Alaska Native, Hawaiian or Pacific Islander, Inupiaq, Dena'ina	70	Some college (did not complete degree)	City (e.g., Anchorage), Small town (e.g., Wasilla), Village (e.g., Kivalina), Hub community (e.g., Bethel)	Yes
Copper	3	Woman	American Indian or Alaska Native, White, Tlingit	86	Doctorate, MD or equivalent professional degree	City (e.g., Anchorage)	Yes, as researcher & participant
Snow Machine	2	Man	American Indian or Alaska Native, Black/African American	38	Some college (did not complete degree)	Hub community (e.g., Bethel)	Yes
Pen	3	Woman	American Indian or Alaska Native	77	High school diploma	City (e.g., Anchorage)	Yes
Dog	3	Man	American Indian or Alaska Native	73	Less than high school	Hub community (e.g., Bethel), Kenai & Kodiak	Yes
Dragonfly	3	Woman	American Indian or Alaska Native	60	Some college (did not complete degree)	City (e.g., Anchorage), Village(e.g., Kivalina)	No

Findings

Themes from our analysis are presented below by coding category.

User Needs

This category captured the specific needs, goals, and objectives for results dissemination as expressed by participants. Participants shared that understanding community interest, needs, and concerns is fundamental to ensuring that research is relevant and impactful. Facilitating dialogue and easy ways to communicate with researchers fosters open communication and collaboration. Visual representations of health, problems, and

culture make information more accessible and relatable. Providing audio and narrative content with captions helps ensure inclusivity for those with different sensory needs and preferences. Participants also suggested offering different versions for Youth and Elders to tailor information to be age-appropriate and engaging for all community members. Sign-up mechanisms like text messaging and email subscriptions help users stay informed and involved. Ensuring access to research articles allows community members to delve deeper into the findings. Incorporating Native language and cultural elements respects and reflects the community's heritage. A solutions-focused approach highlights practical and positive outcomes. Short-form videos provide engaging and digestible content. Finally, integrating health education material enhances understanding and empowers community members to take informed actions.

Pain Points

This category represented the challenges, frustrations, or obstacles participants encountered in their current experiences with research results dissemination information. Participants shared that too many accounts can overwhelm users, making it difficult to manage and access information efficiently. Technology skills highlight the need for training programs to help users navigate digital platforms effectively. Transparency can be lacking, which may lead to mistrust and disengagement. Lack of bandwidth and internet access is a significant barrier, particularly in rural areas, limiting the ability to access and utilize online resources. Addressing these pain points is essential for improving user experience and ensuring equitable access to information and resources.

Design Preferences

This category indicated the design elements, features, or functionalities that participants preferred or prioritized. Several important themes are highlighted. Incorporating Native music can create a culturally resonant and engaging atmosphere. Making information lighthearted for kids ensures that content is accessible and enjoyable for younger audiences. Using Native imagery, such as regalia, art, and cultural backgrounds, helps to ground the information in the community's cultural context. Bright colors,

especially for kids, can make the content more visually appealing and engaging. Presenting visual information in digestible bits, like talking points, makes complex information easier to understand. Finally, using pictures to tell a story can enhance comprehension and retention by providing visual narratives that complement the textual information.

Desired Functionality

This category discussed how the prototype should work and what feature preferences participants had for functionality. Different ways of viewing information ensure that content is accessible and engaging for diverse audiences. Participants recommended a comment section and sharing options to facilitate interaction and community building, allowing users to discuss and disseminate information. Search functionality is crucial for users to efficiently locate specific information. Ways to communicate with researchers provide direct channels for feedback and collaboration. Subscription options help users stay updated with the latest research and developments. Videos with captioning enhance accessibility for those with hearing impairments. Short videos that build on the topic, like a series, offer a structured and engaging way to delve deeper into subjects, making complex information more digestible.

Communication and Collaboration

This category is related to participants' preferences or needs regarding communication and collaboration features. Participants shared that collaborative experience emphasize the importance of considering participants' concerns to foster a more inclusive and effective partnership. Addressing power dynamics ensures that all parties, including participants and researchers, operate on equal footing, promoting mutual respect and equity. The theme of not wanting to be misrepresented underscores the need for accurate representation of participants' perspectives and experiences. Finally, the priority to research highlights the risk of participants' contributions being overlooked, stressing the importance of valuing and integrating their input throughout the research process.

Customization and Personalization

This category indicated participants' interest in customizing or personalizing their experiences. Participants wanted an option to subscribe to updates to ensure that users can stay informed about the latest developments and research findings. Offering content in different languages caters to diverse linguistic needs, making information accessible to a broader audience. Creating different versions for age groups ensures that content is age-appropriate and engaging for all users, from children to adults. Utilizing different methods of dissemination, such as newspapers, email listservs, and other channels, ensures that information reaches users through their preferred mediums, enhancing accessibility and engagement.

Feedback Mechanisms

This category indicated participants' preferences for providing feedback or reporting issues within the prototype. Providing a suggestion box or other ways to provide feedback ensures that community members have a direct and accessible means to share their thoughts and suggestions. Offering a subscription option allows users to stay updated with the latest information and developments, fostering ongoing engagement. Facilitating word of mouth communication leverages traditional and informal channels to spread information effectively within the community, enhancing participation and feedback.

Cultural Sensitivity

This category reflected participants' preferences for culturally sensitive design elements, language choices, and imagery. Visual and graphic representation of different Native communities helps ensure that the diversity and uniqueness of each community are respected and highlighted. Incorporating local context makes the information more relevant and relatable to the community. Using Native languages and cultural backgrounds fosters inclusivity and respect for cultural heritage. Word of mouth methods, like the Mukluk Telegraph, leverage traditional communication channels to disseminate information effectively. Providing visual and auditory information caters to different sensory preferences, enhancing accessibility. Connecting legend stories to modern-day contexts

can make research results more engaging and relatable. Symbolism can be used to convey deeper meanings and cultural significance. Making results sharing a dialogue encourages open communication and mutual understanding. Finally, limiting jargon ensures that information is clear and accessible to all community members.

Community Engagement

This category related to participants' interest in opportunities for community engagement, involvement, or participation in the research dissemination process. Several key themes were highlighted. Being listened to emphasizes the importance of reciprocity, ensuring that community members feel heard and valued. Participants shared that engaging in dialogue with researchers and the community fosters open communication and mutual understanding. Engaging with resources underscores the real-world impact of community involvement, making resources more accessible and relevant. Second-hand engagement through peer interactions can also enhance participation and spread awareness. Access increases engagement, highlighting that providing easy access to information and resources boosts community involvement. Engagement leads to empowerment, moving away from a "lab-rat" mentality and giving community members a sense of agency. Community credit involves recognizing and respecting the contributions of community members, ensuring their consent and involvement in the process. Finally, engagement as a tool for research reliability through community review ensures that research findings are accurate and reflective of the community's perspectives.

Local Relevance

This category indicated participants' preferences for research results that are relevant and applicable to their local community context. Connecting research back to local traditions and community experience/context ensures that findings are meaningful and resonate with the community's social and cultural heritage. Incorporating traditional music, such as Native drums, can enhance cultural connection and engagement. Video clips that give context to the community provide visual narratives that make the information more relatable and impactful. Using data to show changes in the community highlights the

tangible effects of research over time. Community review before sharing publicly ensures that findings are accurate and respectful of community perspectives.
Addressing community priorities aligns research with the needs and concerns of the community. Establishing trust by showing how researchers connect to the community and are trustworthy fosters a collaborative and respectful relationship. Demonstrating how research has a positive impact on the community underscores the value and benefits of the research. Finally, an open forum to get input from the community on results and solutions to issues encourages active participation and empowers community members to contribute to problem-solving.

Accessibility

This category represented participants' needs and preferences for accessible design features that accommodate diverse abilities and access limitations. Several key themes emerged in the analysis. Ease of finding information is crucial, ensuring that users can quickly and efficiently locate the resources they need. Common areas such as libraries and post offices play a significant role in providing accessible information hubs. Advertising and subscribing mechanisms must be straightforward to reach a broad audience. Ability and disability access is essential, incorporating audio, video, and one participant even suggested having braille options for physical dissemination materials to cater to diverse needs. Language accessibility involves offering translations in Native languages and using non-jargon language to ensure clarity of research information. Technology literacy highlights the need for training programs to help users navigate digital platforms effectively. Lastly, rural access to the internet and bandwidth is a factor, addressing the digital divide and ensuring equitable access to information for all.

Trust and Transparency

This category reflected participants' expectations for trustworthiness, transparency, and accountability in the research dissemination process. Community involvement in the review of research results ensures that findings are accurate and reflective of the community's perspectives. Providing access to deidentified data results through platforms

like data websites enhances transparency and allows community members to explore the data independently. Using a tracking number to check the status of a research study offers a practical way for participants to stay informed about the progress of the research. Giving participants community credit for participating in research acknowledges their contributions and fosters a sense of ownership and respect. Demonstrating how research results are being implemented shows the real-world impact and relevance of the findings. Empathy and cultural humility of researchers are crucial for building trust and fostering respectful interactions. Encouraging dialogue ensures open communication and mutual understanding. Avoiding a "talking down to people" approach promotes equality and respect in interactions. Finally, ensuring representation from across the community, not just specific individuals like leaders or extroverts, ensures that diverse voices and perspectives are included in the research process.

Privacy and Data Security

This category indicated participants' concerns and preferences regarding privacy protections and data security measures. Participants felt that closed groups on platforms like Facebook can provide a seemingly secure environment for sharing information while maintaining privacy. They also shared that anonymized data helps ensure that personal information is protected, fostering trust and encouraging participation. Concerns about integration with health records highlight the importance of safeguarding sensitive health information to maintain privacy. On a practical sense, they also shared that having the requirement for username and password might decrease use due to the added complexity and potential barriers to access. Addressing these privacy and data concerns is important for building trust and ensuring that users feel secure and comfortable engaging with research.

Empowerment

This category represented participants' desire for empowerment and agency in accessing, interpreting, and utilizing research results. Elder/youth relationships emphasize the importance of intergenerational connections, fostering mutual respect and learning.

Providing the ability to select what content to receive based on factors like gender and age ensures that information is tailored to individual preferences and needs. Showing respect to the community is fundamental, acknowledging their contributions and perspectives. Participants suggested that a research results review committee would be useful for community members to have a say in the interpretation and dissemination of findings. Increasing access to the role researchers play in the community enhances transparency and trust. Community credit for research participation and contribution recognizes and values the efforts of community members. Maintaining open lines of communication with researchers ensures ongoing dialogue and collaboration. Research done by Native people can support cultural relevance and sensitivity. Finally, actively addressing community wants and needs increases the likelihood that research is aligned with the priorities and concerns of the community.

Community Priorities

This category indicated participants' preferences for research topics or areas of focus that align with community priorities and interests. Participants suggested that images that represent local context such as maps, cultural symbols, and real ANAI people help ground research in the community's reality. Charts, graphs, and rates provide visual clarity and make complex data more accessible. Moreover, seeing how research changes or progresses allows community members to track developments and understand the impact of research over time. Research results grouped by topic (e.g., heart disease, diabetes) facilitate focused discussions and targeted interventions. An emphasis on resiliency, positive perspectives, and solutions highlights the community's strengths and proactive approaches to challenges. Community similarities and personal connections to research foster a sense of relevance and engagement. Strategies to make users a part of the research story ensure that community members feel included and valued. Health education attached to research results enhances understanding and practical application of findings. Finally, quotes and audio provide a personal touch, capturing the voices and experiences of community members directly.

Health Literacy

This category is related to participants' health literacy levels and preferences for clear, understandable communication of research findings. Ensuring content is age-appropriate helps tailor information to different age groups, making it more relevant and understandable. Using terms that are easy to remember and limiting jargon ensures clarity and accessibility. Grouping research studies by health-related topics allows for focused and organized dissemination of information. Showing the effects of research on the community highlights the practical impact and relevance of findings. Making information accessible to a wide range of education levels ensures inclusivity. Emphasizing strengths-based and solutions-focused approaches highlight positive outcomes and actionable steps. Providing actionable results empowers community members to take informed actions. Connecting information to personal experiences makes it more relatable and engaging. Sharing historical context provides background and depth to the information. Finally, fostering conversation and dialogue encourages open communication and mutual understanding.

The next step in the analytic process was to further iterate on the initial pass at analyzing the workshop data. In consolidating the initial thematic analysis, the inductive analysis resulted in themes surrounding: prototype goals, content features, and visual design features. A synopsis of these themes is presented below.

Prototype Goals

Workshop participants designed towards 3 broad goals for what they would want the prototype to accomplish (Figure 1). They shared goals related to **learning** about research results, the history of unethical research in ANAI communities, and health education resources that are relevant to health research topics. They also wanted a prototype that facilitates **communication** – both with one another and with researchers about the results of a research study or other questions. Finally, they shared goals relevant to **finding** – they wanted to be able to find solutions to research problems and to be able to find out what research is happening in their communities and if studies are open for recruitment.

Figure 1. AN Community-Identified Goals for Research Results Prototype

Wireframe Prototype

Using the information shared by participants during co-design sessions, I used Figma to develop a wireframe prototype to get feedback from community stakeholders. The wireframe for the website homepage is below in *Figure 2*. I have also included larger figures of the prototype in the appendices as *Appendix A*.

Figure 2. Prototype Wireframe Homepage

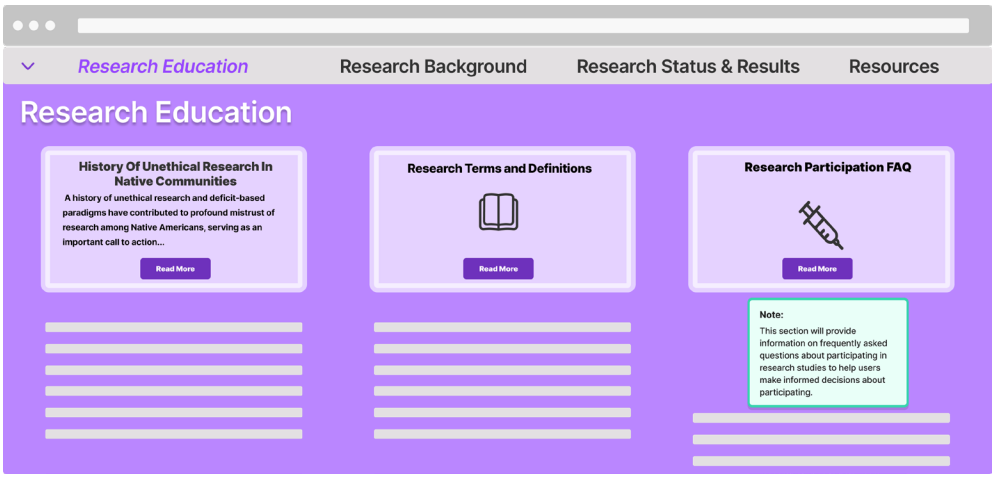
Content Design Features

As far as content, workshop participants focused on five areas during co-design activities including: research education, research background, resources, research status and

results, and communication. These content features are described below with an accompanying figure of the wireframe prototype for each feature.

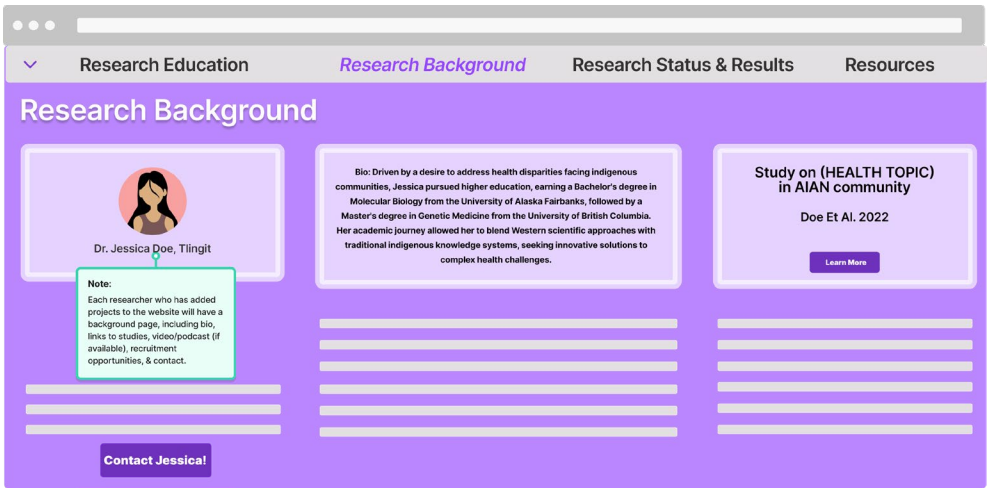
Research education – participants wanted to easily be able to find technical terms and to have jargon defined. They also wanted an acknowledgment of the history of unethical research practice included as part of education about the history of research in our communities.

Figure 2. Research education wireframe prototype



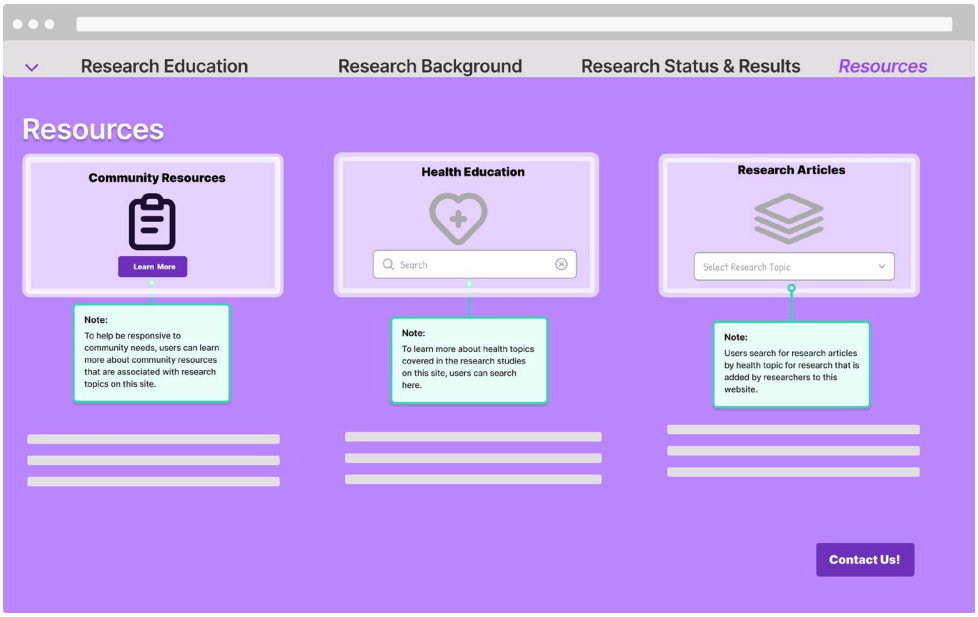
Research background – They wanted more background about researchers, funding sources, study backgrounds, timelines and recruitment status.

Figure 3. Research background wireframe prototype



Resources – They also wanted consolidated access to resources relevant to the research, including who to reach out to for research safety issues (e.g. IRB), and educational resources, not just research education but health education resources relevant to the research topics, resources in the community for topics relevant to the research (e.g. treatment centers, human services), and access to peer reviewed research results (but in addition to non-academic summaries)

Figure 4. Resources wireframe prototype



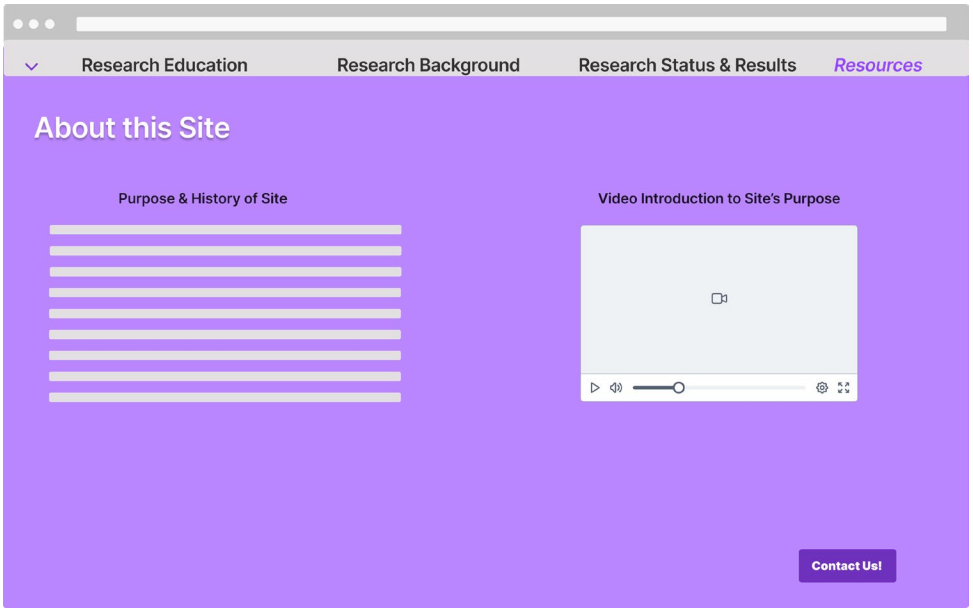
Research Status & Results – And for those summaries they wanted them to be brief, easy to understand, include infographics and multi-modes of dissemination (e.g. text, video, audio, dialogue with researchers and other community members).

Figure 5. Research status and results wireframe prototype

Communication - They also wanted multiple **ways to communicate**. They suggest having a comment feature, integrating results with social media, ability to subscribe to updates and share feedback with researchers and website administrators.

Figure 6. Contact wireframe prototype

Figure 7. About wireframe prototype



Visual Design Features

The visual design features that participants shared related to **community** and **culture**. Participants wanted the prototype to use colors and symbolism that represent different ANAI cultural backgrounds and were dependent on where the research was taking place. They wanted to incorporate cultural activities, such as Native dance, drumming, regalia, and music. They also wanted to see representation from the varied ANAI community groups in the area, in the case of an urban setting, like Anchorage, where so many Tribal groups converge, they wanted to feel represented through relevant cultural stories and use of language and culture.

Conclusion

Feedback on the prototype was gathered through a survey conducted during the University of Washington First Nations Powwow, where we observed how users interacted with the prototype and collected their thoughts, opinions, and suggestions for improvement. Chapter 7 includes more information about prototype user testing.

Chapter 5 Summary & Contributions

This chapter outlines the process of using co-design workshop data to develop the low-fidelity prototype for disseminating health research results to ANAI communities. The research question focused on identifying aspects to include in a prototype for collaborative health research dissemination. The study involved three co-design workshop sessions with 12 ANAI community participants in Anchorage, Alaska, recruited from Southcentral Foundation's Anchorage Native Primary Care Center. Participants represented diverse Tribal heritages and ranged in age from 25 to 86. The workshops introduced concepts of health research dissemination, storytelling, and co-design, culminating in the design of a website prototype. The prototype was developed through thematic analysis of workshop data, focusing on user needs, pain points, design preferences, and functionality. Paper prototyping was used to create wireframes simulating user interactions, which were iteratively refined and generated in Figma. Key themes emerged around prototype goals, content design features, and visual design preferences:

- **Prototype Goals:** Learning about research results, facilitating communication, and finding solutions to research problems.
- **Content Design Features:** Participants wanted research education (e.g., glossary, history of unethical research), research background (e.g., researcher bios, funding sources), resources (e.g., health education, peer-reviewed articles), research status and results (e.g., infographics, podcasts), and communication tools (e.g., comment sections, social media integration).
- **Visual Design Features:** Participants emphasized cultural representation through colors, symbolism, and activities like Native dance, drumming, and storytelling.

A wireframe prototype was developed based on these insights and tested at the University of Washington First Nations Powwow to gather user feedback. Further details on user testing are provided in Chapter 7.

The contributions of this chapter are as follows:

1. **Development of Prototype Framework:** I provide a process for using co-design workshop data to create a low-fidelity prototype for health research results dissemination tailored to ANAI communities.
2. **Community-Centered Design Approach:** I highlight the importance of engaging historically underserved ANAI communities in the design process, ensuring their needs, preferences, and cultural sensitivities are incorporated into the prototype.
3. **Identification of Key Themes for Prototype Design:** I identify themes such as user needs, pain points, design preferences, cultural sensitivity, accessibility, and community engagement, which inform the prototype's goals, content, and visual design features.
4. **Practical Insights for Health Research Dissemination:** I provide actionable insights for creating a tool that facilitates communication, education, and collaboration between researchers and ANAI communities.
5. **Foundation for Future User Testing:** The wireframe prototype serves as a foundation for further user testing and refinement, as discussed in subsequent chapters.

These contributions advance the understanding of how co-design methods can be applied to health research dissemination in culturally diverse and underserved communities.

Chapter 6: Amplifying Cultural Values with Collaborative Photo Elicitation: Strengths-Focused Co-Design with Alaska Native People

This research was previously published (see citation below)

Citation: Dirks, L. G., Belarde-Lewis, M., Pratt, W. (2025). Amplifying Cultural Values with Collaborative Photo Elicitation: Strengths-Focused Co-Design with Alaska Native People. In Proceedings of the 2025 ACM Designing Interactive Systems Conference (DIS '25). Association for Computing Machinery, New York, NY, USA.

Focusing on deficits in research with historically marginalized communities, such as Indigenous communities, perpetuates negative stereotypes and overlooks their strengths and resilience, contributing to mistrust and epistemic injustice. Shifting to strengths-based research approaches promotes more constructive narratives, respects Indigenous knowledge systems, and aligns with ethical frameworks emphasizing Indigenous community ownership and collaboration. We use photo elicitation to investigate values for community-level health research results dissemination with Alaska Native communities, exploring online image search as a tool for collaborative photo elicitation during the co-design ideation process. Our strengths-based approach demonstrates how our methods aid in recalling cultural values during design ideation. Using a deductive qualitative approach, we examined data through lenses of resilience, socioecological strengths, and sociocultural strengths. Cultural representations of community, health and wellness, storytelling, and research are emphasized to illustrate strengths while supporting ideation. We discuss the design implications of using image search for collaborative photo elicitation and its potential for revealing cultural strengths that may otherwise be missed.

CCS CONCEPTS • Human-centered computing • Human computer interaction (HCI) • HCI design and evaluation methods

Additional Keywords and Phrases: Indigenous people, strengths-based research, co-design, photo elicitation

Introduction

Focusing on deficits in research and design can perpetuate negative stereotypes and stigmatization, particularly for marginalized communities, as it often highlights problems and shortcomings. This approach overlooks many of the strengths, resilience, and positive aspects of these communities, which are crucial for promoting potential solutions and constructive initiatives. Previously, deficit-based research has been conducted with Indigenous communities from a colonial perspective, often without the consent or involvement of Indigenous peoples, leading to mistrust and a sense of exploitation [98]. It also contributes to epistemic injustice by devaluing Indigenous knowledge systems and perspectives, failing to recognize their validity and richness [99]. Research that focuses solely on deficits may not lead to meaningful change or improvement, resulting in a cycle of problem identification without addressing root causes or promoting sustainable solutions [100]. In this paper, we propose an alternative approach that shifts towards strengths-based research and design by including culturally supportive image searching integrated into the co-design process. This approach supports Indigenous communities in ways that are respectful, empowering, and aligned with their values and priorities. First, it emphasizes the capacities, resources, and resilience of Indigenous peoples, rather than focusing solely on problems. It also aligns with Indigenous values of well-being, which are often rooted in social, cultural, and ecological factors [101]. By highlighting strengths, this process fosters a more positive and empowering narrative, which can help to build trust and collaboration between researchers and Indigenous communities [102]. Additionally, strengths-based research respects and incorporates Indigenous knowledge systems and perspectives, promoting epistemic justice and validating Indigenous ways of knowing [102]. This approach also aligns with ethical frameworks that emphasize community ownership, control, access, and possession of research, ensuring that the research process and outcomes are beneficial and respectful to the communities involved [103-106].

In this paper, we present our strengths-based photo elicitation approach and provide an analysis of the data collected from its use during design ideation workshops with Alaska Native community members. We take this approach to highlight the resiliency and

overwhelming opportunities that exist in focusing on protective factors of Indigenous community values for the design of systems to support healing from past research injustice. Photo elicitation, a method that uses photographs to evoke deeper insights and reflections, has been increasingly employed in participatory design. While this method is effective in capturing nuanced, qualitative data, the analysis of such data may often have been conducted through a deficit lens [107]. Such a deficit lens limits the potential of photo elicitation to surface positive aspects and strengths within the community. We need to shift towards balancing strengths-based and problem-based usage and analysis in design research involving Indigenous communities. Such a shift would emphasize the capacities, resilience, and positive attributes of the community, fostering more empowering and respectful research and design processes and providing more contextually relevant solutions to problems faced in their communities. By emphasizing strengths, researchers can better align with Indigenous values and principles, promoting epistemic justice and validating Indigenous ways of knowing that can help address problems faced in their communities. This study examines the following research questions:

RQ1: How can photo elicitation be used in co-design to support a resilient and culturally supportive view of Indigenous epistemologies?

RQ2: How might a strengths-based approach help aid in design with Indigenous communities?

This paper addresses a gap in the Human-computer Interaction (HCI) and design literature by exploring the application of strengths-based use and analysis of photo elicitation data in co-design workshops. We demonstrate how this approach can uncover valuable insights and contribute to more effective and culturally sensitive design solutions. Through this research, we seek to highlight the importance of recognizing and leveraging the strengths within Indigenous communities, contributing to more sustainable and helpful design outcomes that are more salient to and respectful of these communities.

Related Work/Background

Research methodologies within HCI and design have revealed significant insights into how different approaches can impact marginalized communities. This section delves into various research paradigms, highlighting both damage-centered and strengths-based methodologies, as well as Indigenous epistemologies and visual techniques like photo elicitation as a tool for design research.

Damage-Centered Research and Design

Damage-centered research, particularly highlighted by Indigenous researcher Eve Tuck (Unangan) in her critical work "Suspending Damage: A Letter to Communities," critiques research practices that focus predominantly on the negative aspects of marginalized communities, such as their struggles and deficits [108]. This damage-centered approach is especially evident in health-related research, as funding typically relies on supporting health-related problems that are viewed as something that needs to be fixed rather than looking at existing practices and resources available to communities experiencing health disparities. Such an approach can inadvertently reinforce harmful stereotypes and perpetuate a narrative of these communities as intrinsically damaged. In the field of HCI, this critique has been extended to examine how such research can overshadow resilience and agency within marginalized communities. Scholars exploring the issues of research that is focused on community deficits advocate for more holistic approaches, such as community-based participatory research, which balances the documentation of oppression with the recognition of community strengths and achievements while also ensuring that any resulting research outcomes can be sustained by the communities involved [109-111]. Ethical considerations in this context emphasize the importance of prioritizing the voices and needs of the communities being studied, encouraging researchers to engage in reflexivity and consider the potential impacts of their work [110, 111]. Moreover, while the challenges faced by historically marginalized communities are significant, the resulting needs from these problems do not solely define their identity, making it important for designers and stakeholders to address their needs while also

fostering what To and colleagues, refer to as self-actualization and flourishing [111]. Chordia and colleagues, in a systematic review of justice-oriented research in HCI found that the literature they reviewed tended to focus on “harms that require justice and social change, including marginalization, exploitation, oppression, and vulnerability” calling HCI researchers to action that narrative deficits can also be balanced with more strengths-based narratives towards more just futures for these communities [112].

Strengths-Based Research Methodology in HCI

As a challenge to damaged-centered research, strengths-based approaches in the HCI and design community have gained traction to emphasize the capacities, capabilities, and resilience of marginalized communities, rather than focusing solely on their deficits. Strengths-based approaches align with participatory and community-centered design principles, fostering more inclusive and empowering research practices [113].

The strengths-based methodologies used in HCI and design are varied and include approaches such as Research Through Design, Asset-based Design, and Appreciative Inquiry. Broadly speaking, Research Through Design integrates design practices into HCI research to generate new knowledge by understanding current states and suggesting improved future states through design. This methodology emphasizes iterative understanding and deep reflection on people, problems, and contexts, promoting a more strengths-based perspective than simply viewing only the deficits [114, 115]. Another significant contribution is the work on elevating strengths and capacities within communities facing historical inequities through asset-based research. Researchers in this area have explored alternative approaches to designing with communities, focusing on assets and strengths rather than deficits [116-119]. This asset-based research approach has been particularly effective in creating more equitable and respectful design processes [120]. Appreciative Inquiry in HCI and design research focuses on identifying and leveraging strengths to create innovative solutions. By following a four-stage process—Discovery, Dream, Design, and Destiny—Appreciative Inquiry fosters a positive and collaborative environment that encourages stakeholders to share their experiences and aspirations [121]. Mirkovic and colleagues found that incorporating Appreciative Inquiry with their

participatory and service design research enhanced participant engagement, reflections, and creativity, leading to innovative ideas that went beyond problem-solving and addressed participants' strengths and values [122]. Hall et al (2024) in their design research to support neurodiversity in the workplace concluded that designing workplace supportive technology for individuals with intellectual and developmental disabilities (IDD) should focus on enhancing their independence by leveraging their strengths, such as relationships and reliability. By supporting cognitive processes and personalizing features to users' inherent strategies, technology can facilitate independence and agency, moving beyond deficit-based designs [123].

While strengths-based methodologies offer many benefits, there are also arguments against their use in HCI and design research. Focusing primarily on strengths can sometimes lead to the neglect of significant problems and challenges that need to be addressed, resulting in an incomplete understanding of the community's needs and hindering the development of effective solutions[124]. Additionally, strengths-based approaches might inadvertently lead to superficial engagement with communities, missing deeper, systemic issues that require attention and intervention[124]. There is also a risk of bias towards positive outcomes, which can skew research findings and lead to overly optimistic conclusions that do not accurately reflect the reality of the community's situation. Implementing these approaches can also be resource-intensive, requiring considerable time and effort to build trust, engage deeply with communities, and identify their strengths, which can be a barrier for researchers with limited resources. There is also a risk that strengths-based methodologies can be used superficially, as a form of tokenism, without genuinely addressing the underlying issues, undermining the credibility and effectiveness of the research. Though strengths-based approaches are valuable for challenging deficits in research with marginalized groups, these valid criticisms necessitate balancing strengths with community deficits in research and design [111, 112, 124].

Indigenous Epistemologies & Research

Incorporating strengths-based research approaches is a significant step towards decolonizing research. Many Indigenous scholars assert that Indigenous methodologies

focus on collective community needs entrenched in holistic relationships between people, their values, beliefs, and connections to the physical world versus individual needs [105, 125-127]. In this sense, since knowledge is intertwined with daily existence, it can be difficult to categorize and systematically define with empirical approaches [35]. In contrast to positivist social science approaches, where the goal of science is to predict and control behavior, Indigenous research methodologies do not prioritize predicting or controlling behaviors but focus on relationality between constructs such as people and their physical, social, and spiritual environment [128]. As an outcome of Indigenous communities' rights for Tribal research sovereignty, community engagement in research has become the norm. Indigenous community members are often engaged throughout the research process. This comprises collaboration that occurs during the entire research process including conceptualizing research topics, developing research questions, collecting, analyzing, and interpreting data, and disseminating study results [8, 12-14, 129]. Ongoing multidirectional communication encourages trust and allows communication to flow so information remains relevant to the community [14, 17, 93, 94]. For Indigenous communities this includes relevance to local context including local values, knowledge, and expertise [84-86] while also highlighting existing community strengths.

Photo Elicitation

In the HCI and design literature, photo elicitation methods have been effectively used to capture rich, qualitative data and engage participants. Photo elicitation is useful for developing a shared understanding between researchers and participants and can be done through photographs that were taken by participants, collected by participants, or selected by researchers[130-132]. These methods are particularly relevant to strengths-based research with Indigenous communities, as they can help highlight cultural assets and resilience. Photo-Elicitation interviews use photographs to prompt discussion during interviews, eliciting detailed personal narratives and reflections, making them suitable for understanding participants' perspectives and experiences [133-136]. Photovoice, a participatory photography method, aims to empower participants to capture and discuss images representing their experiences and viewpoints, promoting critical dialogue and

community-driven change [137-139]. This approach aligns well with strengths-based approaches by enabling community members to document and share their strengths. Visual elicitation techniques, which include various forms of visual stimuli such as drawings or collages, facilitate discussion and reflection, providing a platform for participants to express their strengths and aspirations [140, 141]. Participatory photography involves participants taking photographs that are then used as a basis for discussion and analysis, effectively engaging marginalized communities and allowing them to highlight their strengths and assets [142, 143]. For Indigenous communities, participatory photographic elicitation methods can reveal everyday resilience and cultural richness [144-146]. Though many photo elicitation methods, such as Photovoice and participatory photography use an approach where images are collected and created directly from participants, other photo elicitation approaches ask participants to provide feedback on images that they did not directly collect themselves. For example, studies in health sciences have used photographs from archives to elicit feedback from participants[147-149] and to prompt discussion from users from researcher-generated photographs[150, 151]. Visual elicitation methods have potential to respect and amplify the perspectives of Indigenous communities, helping to ensure that their strengths and assets are recognized and valued in the research process.

Methods

To gain an understanding of how to incorporate community strengths and resiliency during co-design, we employed a culturally focused photo elicitation activity during the ideation phase of co-design workshops. We used a qualitative analytic approach to gain an understanding of community strengths and resiliency as seen in image search data collected during co-design ideation workshops. First, we share information about the ethics review process for conducting this research. Next, we explain the design process used for photo elicitation data collection. Then we share information about the analytic approach used to explore strengths within the data. Finally, we share information about participant characteristics.

Ethics Review

This research went through multiple ethics review processes before data were collected for this study. We received approval from the University of Washington Institutional Review Board, the Alaska Native Tribal Health Consortium's Alaska Area Institutional Review Board, and the Southcentral Foundation Research Oversight Committee. The Alaska Native Tribal Health Consortium IRB oversees all health-related research conducted within the Alaska Native Medical Center healthcare system. Southcentral Foundation, located within this healthcare system, is a Tribal healthcare facility that requires all research conducted within their organization to go through their own internal research review process prior to conducting research with their stakeholders. Their review process also involves a Tribal review process in which Tribal leaders provide feedback, not only on the research protocol, but all research instruments and processes. We were required to make changes to instruments and procedures based on this feedback before any research activity took place.

Design Method

We conducted a three-session series of four co-design workshops with Alaska Native community participants. The purpose of the workshop series was to co-design tools for community collaboration in the health research dissemination process. The series included three sessions that occurred within a one-week period. Session 1 (1.5 hours long) introduced participants to background and concepts of health research results dissemination, storytelling, and co-design, including the preparatory photo elicitation activity that this paper is focused on. Session 2 (2.5 hours long) delved deeper into the co-design process and involved activities to co-design tools for Alaska Native people to collaborate with health researchers to share research results with Alaska Native communities. In session 3 (2 hours long), participants then used design ideas from previous sessions to co-design a prototype for Alaska Native health research results dissemination.

In this paper, we focus on design activity from Session 1 which introduced participants to concepts of health research results dissemination and storytelling, and gave participants an opportunity to help shape the workshop series agenda. This section includes a description of the design activity we conducted in Session 1, an opening photo elicitation activity

intended to introduce participants to health research and storytelling concepts, as well as design ideation. This initial workshop activity helped prepare participants for prototyping activities for later sessions in the workshop series and develop rapport amongst the group. We used Google Image Search to explore visual representations of relevant topics—community, health and wellness, storytelling, and research—for the larger co-design study. The workshop facilitator, who is also Alaska Native, led all search activity and projected search results on a white board so that all participants were able to see the search results. For each concept (e.g., community, health and wellness, storytelling, research), participants were asked to visually scan the image results and share aloud when they saw an image that represented the concept from their perspective. The workshop facilitator then added the images to a Google Jamboard, compiled by concept, for the group to see and reflect on together. The workshop facilitator also asked participants to articulate how that image represented the concept in question with other participants adding to their interpretation. For example, the facilitator asked, “How does this image represent Alaska Native health and wellness to you?” followed by additional prompts that were based on participant feedback. All search queries began systematically with a broad search term by concept (e.g., Alaska Native Health and Wellness) and became more granular (e.g., Alaska Native Traditional Medicine). Following the initial search, the workshop facilitator invited participants to recommend additional relevant search terms to query for more nuanced results. Table 1 includes the sequence of the search result query terms.

Table 1 - Photo Elicitation Search Query Progression.

		Additional Search Queries (by workshop group)			
Topic	**Initial Search Query**	**Group 1 (n=4)**	**Group 2 (n=2)**	**Group 3 (n=4)**	**Group 4 (n=2)**
Community	Alaska Native Community	● Alaska Native community whaling ● Savoonga Alaska Whaling (village in Alaska) ● Point Hope Whaling (village in Alaska) ● Alaska Native gathering ● Alaska Native church	● Fairbanks (community in Alaska) ● Alaska Native culture	● Alaska Native gathering ● Alaska Native Map	● Alaska Native Village
Health and Wellness	Alaska Native Health and Wellness	● Alaska Native Health ● Norton Sound Health Corporation (Alaska Native healthcare facility) ● Tribal doctor ● Tribal healing	● Native health and wellness ● Alaska Native traditional medicine	● Southcentral Foundation (Anchorage Native healthcare services) ● Alaska Native subsistence ● Sauna Alaska Native	● Alaska Native Traditional healing ● Southcentral Foundation wellness center ● Native Youth Olympics ● Going for a walk Alaska Native
Storytelling	Alaska Native Storytelling	● Alaska Native dance ● Alaska Native kids in library ● Alaska Native social media	No additional queries	● Alaska Native Mask ● Alaska Native Art	● Alaska Native Art ● Alaska Native Dancers ● Totem pole ● Storyboard ● Alaska Native library
Research	Alaska Native Research	● Research Alaska Native ● Alaska Native subsistence	No additional queries	● Alaska Native salmon count ● Alaska Fish and Game ● Alaska Native language preservation	

Analytic Method

Though we did not consciously intend to focus on community strengths in the design of this research, the photo elicitation activities we implemented brought out the strengths participants saw within their cultures and communities. We found that this necessitated analyzing the data using a strengths-focused approach. We used a deductive qualitative framework [152] to explore strengths in participant elicitation responses. Our analysis was informed by health science research literature conducted in Indigenous communities. Bryant et al. 2021 identified three categories of strengths-based approaches represented in Indigenous health research—resilience, socio-ecological, and socio-cultural

approaches[102]. *Resilience* approaches focus on individual attributes like skills, attitudes and cognition "that can be drawn upon to manage stress…and can be learned" [102]. *Socio-ecological* approaches also consider individualist attributes and include a person's individual, interpersonal and structural setting's influence on their wellbeing, while *sociocultural* approaches view strengths in relation to social ties, collective practices, and shared identities. Strengths are represented both at individual and collective levels. We used these categories of strengths to code transcript and image data collected during design ideation workshops.

Participant Characteristics

Participants in this study represent a historically underserved and understudied population, particularly within the HCI and design field. Alaska Native communities (229 federally recognized Tribes) are composed of multiple, diverse, smaller groups of individuals who may have relocated to urban settings from a variety of rural, geographically, and environmentally diverse regions across Alaska and the continental United States. Participants in this study do not represent all Alaska Native cultural heritage perspectives but provide a glimpse.

Table 2 – Participant characteristics

Participant	# Workshops Attended (out of 3)	Gender	Heritage	Age	Education	Setting where most time spent in Alaska	Research participation experience
Jellyfish	3	Woman	American Indian or Alaska Native, White	35	Training or technical education	City (e.g., Anchorage)	Yes
Hamster	3	Woman	American Indian or Alaska Native, White	27	Training or technical education	City (e.g., Anchorage)	Yes
Raven	3	Woman	American Indian or Alaska Native	55	High school diploma	Village (e.g., Kivalina	Yes
Orca	3	Woman	American Indian or Alaska Native	60	High school diploma	City (e.g., Anchorage)	Yes
Polar bear	3	Woman	American Indian or Alaska Native, Mexican	59	High school diploma	City (e.g., Anchorage)	Yes
Cat	3	Woman	American Indian or Alaska Native	25	Bachelor's degree	City (e.g., Anchorage), Small town	Yes, as researcher

						(e.g., Wasilla)	
Ivory	2	Man	American Indian or Alaska Native, Hawaiian or Pacific Islander, Inupiaq, Dena'ina	70	Some college (did not complete degree)	City (e.g., Anchorage), Small town (e.g., Wasilla), Village (e.g., Kivalina), Hub community (e.g., Bethel)	Yes
Copper	3	Woman	American Indian or Alaska Native, White, Tlingit	86	Doctorate, MD or equivalent professional degree	City (e.g., Anchorage)	Yes, as researcher & participant
Snow Machine	2	Man	American Indian or Alaska Native, Black/African American	38	Some college (did not complete degree)	Hub community (e.g., Bethel)	Yes
Pen	3	Woman	American Indian or Alaska Native	77	High school diploma	City (e.g., Anchorage)	Yes
Dog	3	Man	American Indian or Alaska Native	73	Less than high school	Hub community (e.g., Bethel), Kenai & Kodiak	Yes
Dragonfly	3	Woman	American Indian or Alaska Native	60	Some college (did not complete degree)	City (e.g., Anchorage), Village (e.g., Kivalina	No

We collected data from December 2023 to February 2024 from participants residing in Anchorage, Alaska during the time of data collection. We recruited participants at a recruitment table set up in the main lobby of Southcentral Foundation's Anchorage Native Primary Care Center, a healthcare facility for American Indian and Alaska Native people. They were given information about the study and activities involved in the design workshops, including the expectation that they would attend all design sessions. Then researchers later contacted them by phone and/or email to schedule workshop participation. A total of 12 Alaska Native community members participated in the design workshops. Participant Tribal heritage was diverse, including participants who self-identified, to the workshop facilitator, as Inupiaq, Athabascan, Tlingit, Aleut, and Yupik. Most self-identified as women (75%, n=9). Their age range was 25-86 years old with an average age of 55. All but one participant had prior experience as a participant in at least one health research study. Participants were

assigned unique identifiers based on nouns (e.g., cat, snow machine, etc.) that they selected during data collection for anonymity and will be referenced as such in the findings for this paper.

Findings

Using our strengths-based analytic framework, we identified Alaska Native contextual strengths in the study's photo elicitation activity data. These findings are categorized into community strengths, health and wellness strengths, storytelling strengths, and research strengths and are highlighted below in their respective sections.

Community Strengths

In taking a strengths-based approach to analyzing the ***Community*** image search data, resiliency among the participants is rooted in collective strengths and cultural practices that foster unity and support. Aligning with a sociocultural approach, participants emphasized the importance of groups coming together in community, highlighting how collective identity and mutual support help individuals manage challenges by relying on the strength of the communal group. Understanding where people are from and the languages they speak fosters a sense of belonging and respect, making individuals feel seen and valued. It also showcases the Alaska Native community's diversity and breadth within the entire state of Alaska (Image 1). In reflecting on ***(Image 1's)*** representation of community, participant Raven shared that the map displays "*where people are from and what kind of language they speak. So that way you could get a little bit of understanding of them*".

Cultural gatherings, such as seen in (***Image 2)***, where people share stories, dance, and celebrate their heritage, provide opportunities for cultural expression and community bonding. Participant Hamster shared that the image "*reminds me of when I was younger, people getting together at the Heritage Center [Alaska Native culture museum] and dancing and getting together from all different types of Indigenous people just coming together and hanging out and hearing stories and dancing*". Gatherings such as these reinforce positive

coping skills and respectful attitudes towards oneself and others and creates a shared identity among diverse Alaska Native peoples.

Image 1 – Map of Alaska Native Language Families

Image 2 – Athabascan gathering dancing

The depiction of Yupik women in regalia (***Image 3***) and the generational transfer of knowledge from elders to younger community members (***Image 4***) highlight the importance of **cultural continuity** or as participant Polar Bear put it, "*generations of what the women teach each other*". This connection to heritage and tradition supports a coherent sense of self and resilience. Activities like working together as a large group on a seal skin blanket as seen in (***Image 5)*** illustrate the power of collective effort and cooperation, enhancing problem-solving skills, and the ability to advocate together with others within the community. Participant Cat emphasized this by stating "*the focus [in the image] is on the hands and everyone holding the seal skin blanket together and how everyone's circled around facing one another and how there's just so many people coming together to make this happen*".

Image 3 – Yupik Women and Children dancing in regalia

Image 4 – Women of different generations dressed in Alutiiq regalia

Image 5 – Tanned seal skin blanket being stretched by large group of people in a circle for blanket toss

Memories of a close-knit community, like in many Alaska Native villages (***Images 6 & 7***), where everyone knows one another, exemplify the **supportive network** fundamental to community strength. This environment, from a strength's perspective, nurtures respectful attitudes towards one another and a powerful sense of identity. Participant Snowmachine shared that "*this [image 6] reminded me of my grandmother who grew up in Nome. She loves to tell me about all of her stories and her memories from when she lived in Koyuk in the villages up there, specifically when she was a kid as well. And she had a lot of friends and everyone kind of knew everybody…. It just reminded me of how tightknit the community is*".

Image 6 – An Alaska Native village with houses in the background

Image 7 – Arial shot of an Alaska Native village

Health and Wellness Strengths

Health and wellness, as seen by participants, is connected to the natural environment, physical activity, community support systems, and cultural practices.

Image 8 – Artwork of a scene with a dark bare tree, roots, birds, plants and orange sunset with blue water or mountains

The **natural environment,** including elements like trees, birds, water, and mountains, is integral to health and wellbeing. In considering this sentiment, Participant Copper described why they selected (***Image 8)*** to represent health and wellness sharing that the image "*represents the earth, the tree, the birds, growing things. It looks like water in the back and the mountains. The natural environment that we would like to live in*" highlighting the importance of the physical environment to health and wellbeing. Walking with ancestors and drawing on ancestral memories emphasizes the importance of cultural heritage, and the wisdom passed down through generations, providing a solid foundation for resilience regardless of how positive the memory might be.

Encouraging **physical activity**, such as a child playing basketball as seen in (***Image 9)***, emphasizes the socioecological importance of staying active and engaged, which helps in developing coping skills and maintaining physical health. Participant Copper shared the following about how this image depicts health and wellness as follows "*She's, out there. She's not on her darn cell phone. She's active. She's moving and enjoying herself and she's so happy. Not just a personal exchange. She isn't texting somebody…*" Elders teaching youth about exercise (***Image 10***) and the benefits of walking for fresh air and meditation highlight the importance of intergenerational support and physical activity.

Image 9 – Young person playing basketball

Image 10 – A young person and an elder exercising

Social interactions and community support systems, such as sharing coffee or tea (***Image 11***), are important for mental health, as these moments of connection and support help individuals feel valued and understood. Participant Cat shared that "*this graphic that has one set of hands holding another set of hands and they're having coffee or tea, and I think that's pretty good illustration of just social time and taking care of your mental health and taking a nice break*". Tribal Healthcare organizations like Southcentral Foundation (SCF) (***Image 12***) and the Alaska Native Medical Center (***Image 13***) provide structured support for health and wellness, including wellness hours for employees, helping individuals manage stress and maintain balance in their lives. Participant Orca, an employee of SCF, shared "*When I think of health and wellbeing, I think of SCF, because as an employee there not only do we get our lunches, but we get an hour of wellness each week and they say that we can use it for mental, physical, emotional and spiritual wellness. So, we're having a hard day, we can take an hour off for that day and kind of just focus on ourselves or we can use it for appointments and stuff like that. And I think that's important so that you are not overworking yourself at work and you can't go to your own appointments and stuff like that*".

Image 11–Two people holding hands while drinking hot beverages

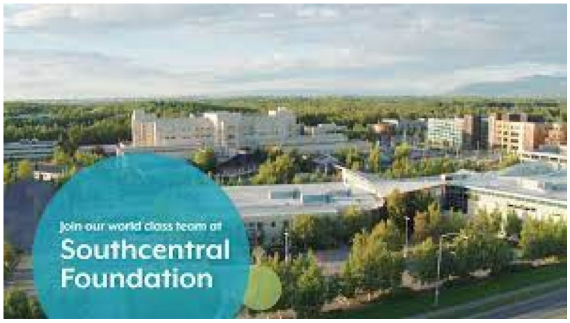


Image 12 – Arial image of the Southcentral Foundation health campus in Anchorage, AK

ALASKA NATIVE TRIBAL HEALTH CONSORTIUM

Image 13 – Alaska Native Tribal Health Consortium logo

Engaging in **cultural subsistence activities** like hunting, fishing, and gathering Alaska Native foods (I***mage 14***) connects individuals to their culture and environment, promoting physical health and a sense of purpose. The practice of using a sauna or steam bath (***Image 15***) for relaxation and stress relief illustrates the importance of traditional methods for managing mental and physical health. Participant Orca shared that "*You could go in [to the sauna/steam bath] grumpy and you could, for me, my experience was went in grumpy, me against the heat, and if I burn my skin I go back out and I feel like 10% better. I'm not grumpy anymore. I'm a little bit more relaxed, but I'm still grumpy, so I'll go back in*".

Image 14 – Women preparing salmon to be hung and dried for processing

Image 15 – Inside of a sauna or steam bath

Traditional healing practices, including plant medicine (***Image 16***), provide knowledge and skills that support community strengths, emphasizing the importance of cultural continuity and self-care. The use of traditional medicines like devil's club and stinkweed salve reflects an interest in cultural practices for healing, supporting a holistic view of health that includes physical, emotional, and spiritual wellbeing. In addition to plant medicine, participants shared that Western medicine also represents health and wellbeing. For example, participant Polar Bear saw pharmacies and pharmacists (***Image 17)*** as beneficial to health "*because the pharmacy keeps us up to date and tells us whether the medication works for you so they [pharmacists] can answer all your questions*." Consuming traditional foods like salmon (***Image 18***) is not only nutritionally beneficial but also connects individuals to their cultural heritage, supporting both physical health and a sense of identity. Participant Cat shared "*I think salmon's one of my favorite foods. One, I just love the taste, but two, it's also just when I eat, it feels very revitalizing and ..., it's like the fish oils and protein that comes with it is always recommended to me whenever I go to see a dietician there at the clinic*".

Image 16– People preparing plants in a garden

Image 17 - Pharmacist consulting patient

Image 18 – salmon hung outdoors to dry

Storytelling Strengths

Strengths in storytelling, as seen by participants, are reflected through the preservation and sharing of intergenerational connections, cultural narratives, and the use of various mediums to convey and share stories.

Image 19– A group of children presumably at a boarding school

Storytelling fosters **connections between generations**, allowing the transfer of knowledge and values, strengthening community resilience. Stories about significant historical and cultural transitions, such as those involving boarding schools, help individuals understand and cope with changes in their community and personal lives. (***Image 19***) shows a photograph of young Alaska Native children taken during their time in a boarding school. Participant Ivory shared the following about how this image depicts an important

transitional period for many Alaska Native and American Indian people "*It's a transitional story. It looks like a boarding school. Indoctrination of maybe children. Assimilation story*".

The use of stories and storytelling plays an influential role in Alaska Native cultures. Some Alaska Native cultural groups, such as the Yupik people, have special tools that are designed to share stories about community life, behavior, and values. Yupik women and girls have utilized these tools, known as story knives, made of wood, ivory, bone, and, more recently, metal to visually tell stories by drawing them in the dirt or snow [153]. Participant Dragonfly described storyknifing "*as they're telling the story, the images are drawn and then as they turn the page, they wipe it [the drawing] out and they do a new one [drawing] as they go along [to tell the story]*." The use of a story knife (***Image 20***), where images are created and then wiped away, symbolizes the dynamic and evolving nature of stories, fostering creativity and adaptability.

Image 20 – Alaska Native elder using a story knife in the dirt to draw a story

Elders sharing stories, whether through a microphone (***Image 21***) or in person as a group (***Image 22***), provide a vital link to the past, offering wisdom and lessons that help younger generations navigate their own challenges. Engaging children in storytelling ensures the continuation of cultural knowledge and traditions, helping them develop a sense of identity and belonging. Participant Raven shared that "*when you talk to the elders, you learn a lot from them about how they used to live a long time ago. And then I also learned where my grandparents originally came from. That's where my family originally came from. And then we moved to Anchorage, and I'm blessed to know who my grandparents were and how they*

taught my parents, and then how we learn and how we teach our children by the stories that they share and their experiences." Family gatherings and shared meals offer opportunities for storytelling and learning, reinforcing family bonds and cultural values, contributing to emotional and social resilience as highlighted by (***Image 23)*** which shows a woman with children sitting at a table together. Participant Polar Bear shared that to her the image "*represents family and culture and because we learn when it's sitting at the table, that's when we get to learn more about each other*".

Image 21 – Yupik elder woman seated in front of a microphone

Image 22– Woman on stage in front of children

Image 23 – Women and children at a dinner table

Symbolic, spiritual and physical expressions of storytelling, such as done through Alaska Native dance (***Image 24***), help individuals connect with their heritage and find strength in their cultural identity. For example, participant Ivory shared "*the motions that the dancers use tell a story about the way of life for each group depending on where they come from*". While Participant Snowmachine, when asked what ways dance tell

Image 24 – Unangax dancers dancing on a stage

stories shared "*could be the type of story about hunting or berry picking or the things that they do to survive, even war*". Song and dance are powerful methods of storytelling that engage the community and create a shared experience, helping individuals connect emotionally and spiritually, reinforcing communal bonds. Participant Cat shared that song and dance are "*another art form of storytelling that's impacted me. Especially if it's a live show or you're in the live audience and feeling the energy in the room when there's a performance going on. It's a direct connection to just the group and the people around you*". Traditional symbolic art forms like totem poles (***Image 25***) and masks (***Image 26***) tell stories about family lineage and cultural heritage, serving as physical representations of identity and history, reinforcing a sense of continuity. Participant Jellyfish shared that "*[Yupik] masks do tell, they facilitate the storytelling in, well mainly the dancing, but you bring upon the kind of qualities of mask that you're wearing, and it helps you get into that spiritual realm of storytelling that it just helps you go into the other world. And I think that's another thing about storytelling is it can be very spiritual and yeah, I think it's [storytelling] very important in Native culture*". While Participant Dragonfly shared about totem poles' function as story stating, "*each figure represents a person or a figure or an event and as you go, I can't remember if it's up or down, but there's a story told with each rung, so to speak, and it gives some information about community and family and the ties to the land and the sea*." Symbolic art forms, such as totem poles, masks, and other visual representations, convey important cultural messages, helping maintain cultural continuity and providing a sense of identity and belonging.

Image 25 – Totem pole in winter

Image 26 – Alaska Native Mask

Physical books and libraries (***Image 27***) as repositories of stories ensure that knowledge is preserved and accessible, providing a communal space for learning and sharing, which supports intellectual and cultural resilience. Participant Cat shared that libraries encompass storytelling because they are an "*amassing of all sorts of different works from people all over the world and also people from your own community. And it's typically a free resource, public resource, I guess I could say, that's accessible to everyone. And just the idea behind libraries is the importance to pass along knowledge without barriers in a way, and that's accessible to everyone in the community without a charge*.

Image 27 – Colorful books on a shelf

Research Strengths

Resiliency in research within the Alaska Native community participants is reflected through the integration of traditional knowledge, cultural practices, use and investigation of natural resources, and support for Western research processes and discoveries. Participant Polar Bear felt research should be valued and saw importance in "*respecting the research because we're trying to help our community learn about themselves*".

In addition to art being viewed as a storytelling mechanism, some participants also viewed **art as relative to research**. Art, such as masks depicting scenes of drying fish, harvesting, and dog sledding (***Image 28***), may serve as a visual representation of traditional knowledge (research) and practices. This artistic expression can help preserve and communicate important cultural information, fostering a sense of identity and continuity. Others also stressed that research can be represented visually, and that, as participant Polar Bear shared, it "*doesn't have to use words, we can actually use pictures*" to represent research results.

Image 28 – Inupiaq artwork of a mask and village scene with dog sled, people and animals

The process of relearning **traditional methods for utilizing natural resources** emphasizes the importance of cultural heritage and environmental stewardship, supporting resilience by ensuring that valuable skills and knowledge are passed down through generations. Participant Hamster saw value in research related to Alaska Native language preservation in supporting cultural heritage preservation stating "*there's many Native languages that are considered endangered. For example, Eyak. Well, my [relative] told me that she's a translator, she's an Eyak translator, and she's helping to preserve it by working with different organizations to facilitate learning. So that's kind of research for the user*". Engaging in activities, such as the blanket toss (***Image 29***), are being done not only as a form of entertainment but also may serve as research and traditional knowledge to help prepare the community for hunting and gathering. Participant Dog viewed the blanket toss as a way Inupiaq people used it as a form of research "*to see further away in [the] ocean or in the air somewhere…whatever they're looking at*". These activities are not only cultural practices but also ingenious practical methods for assessing environmental conditions, such as ice flow, to gauge readiness for subsistence activities like whale or seal hunting or seasonal changes. Participant Pen shared that berry picking (***Image 30***) can help gauge environmental

conditions "*quality of berries or the amount [that are growing] for the season. And I guess they could put into perspective when the Fall season started or started the previous year and stuff. There's a lot of research in berries*". These approaches to researching the environment highlight the adaptive and resourceful nature of the community.

Image 29– Person in the air during a seal skin blanket toss

Image 30– Cranberries and blueberries in containers

Participants image search elicitation also resulted in views of Western scientific research as important to participants' communities. For example, Participant Hamster shared the importance of wildlife tracking research, specifically recording how many salmon are available in rivers "*so we don't overfish it and just do more harm than we intended*". While others interpreted lab-based research (***Images 31 & 32***) and scientific graphs and infographics (***Image 33***) as important to represent research.

Image 31– Two women in a scientific laboratory

Image 32– Woman being recorded with an audio device, presumably for a research interview

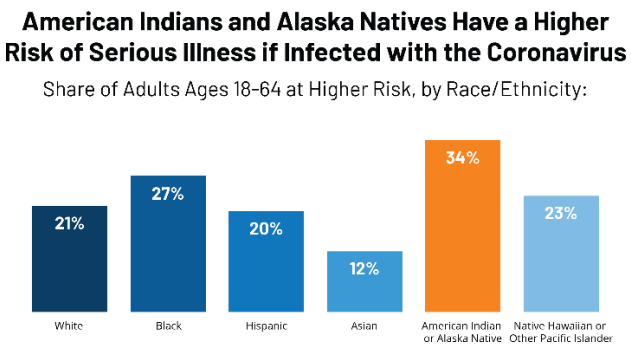


Image 33– Chart from Covid-19 research study Source: KFF

Discussion

The findings from our study underscore how a strengths-based co-design approach can fuel the integration of traditional knowledge and cultural practices into design, as evidenced by the photo elicitation data showcasing visual imagery that depict snapshots of daily life, history, and individual and communal values, and highlights interest in preserving and communicating cultural heritage. This expression not only fosters a sense of identity and continuity but also serves as a powerful tool for resistance against narratives enabled through stereotypes of Alaska Native communities' deficits. The process of employing traditional methods for utilizing natural resources further emphasizes the community's dedication to cultural heritage and environmental stewardship. By passing down valuable skills and knowledge through generations, Alaska Native communities ensure the sustainability of their practices and reinforce their strengths. Engaging in traditional activities, such as the blanket toss, illustrates the adaptive and resourceful nature of the Inupiaq community. These activities are not only cultural practices but also practical methods for assessing environmental conditions and readiness for subsistence activities like whale or seal hunting. This approach demonstrates the community's ability to adapt to changing environments while maintaining their cultural identity. The importance of how stories are used to connect to community and culture underlines an important means to establishing connection and intergenerational knowledge sharing.

Resonance of Strengths

These ideas of strength resounded throughout the remainder of our co-design activities and were significant in the design of the research results dissemination prototypes that participants designed in session 3 of our workshop series. The prototypes incorporated many of the community strengths that were shared during this activity. Prototypes incorporated Alaska Native language, art, and culture within their designs. Participants also designed for a health research dissemination tool that is more communal than standard results dissemination approaches. Rather than designing a journal article or conference presentation, participants designed for web-based tools to share knowledge, learn, and communicate about research results. Participants wanted to be able to communicate not only with researchers but also have conversations with other community members about the research results through active dialogue. They also designed towards prototypes that engage both Youth and Elders showcasing the strength of intergenerational knowledge that was also seen in our photo elicitation data. Participants also designed tools that included mechanisms to share resources to address health problems focused on in research studies. For example, participants included resources for health education and traditional Alaska Native medicine information for interests like healthy eating to decrease obesity and risks towards diabetes and other chronic diseases.

Incorporating HCI and design principles into this context, we recognize the importance of designing research tools and methodologies that are culturally sensitive and inclusive. HCI researchers can better support Alaska Native and other marginalized communities by reflecting on their strengths rather than primarily considering only their deficits. This strengths-based approach can be implemented through:

Culturally Sensitive Design: Developing design approaches that respect and reflect the cultural values and practices of the community. Such approaches would include using culturally appropriate strategies that emphasize community strengths and the usefulness of design improving upon those assets to challenge community problems.

Community-Centered Research: Engaging community members in the design and development process to ensure that the tools and methodologies align with their needs

and preferences. This participatory approach can help build trust and ensure that the research outcomes are meaningful and beneficial to the community.

Strengths-Based Framework: Shifting the focus from only deficits to also including strengths by highlighting the community's resilience, adaptability, and resourcefulness. This approach can empower the community and promote more positive narratives that celebrate cultural heritage and epistemological contributions while also tackling the problems faced.

By integrating HCI and design principles with a strengths-based framework, researchers can enhance the impact of the community's strengths, ensuring that they are supported and celebrated in a modern context. This approach may help empower the community to leverage technology in ways that are meaningful and respectful of their traditions.

Visual Imagery vs Traditional Interview

The data from our study highlight significant advantages of using visual imagery over interview or focus group methods often used in research, particularly among the Alaska Native community members who participated in our study. Visual imagery serves as a powerful tool for capturing and communicating traditional knowledge and cultural practices. Intrinsically, participants elicited strengths they saw within the Alaska Native community overall within each category of image search. This approach offers several key benefits: Visual imagery resonates deeply with the cultural values and practices of the Alaska Native community. It provides an engaging and relatable medium for participants to express their experiences and knowledge, fostering a stronger connection to the research process. Visual representations can convey complex cultural information and emotions that may be difficult to articulate through words alone. Art and imagery capture nuances and details that might be overlooked or inadequately expressed in verbal responses, leading to a richer and more comprehensive understanding of the community's strengths and practices. Visual methods can be more accessible to community members who may have varying levels of comfort and proficiency with oral communication. This inclusivity ensures that a broader range of perspectives are represented in the research. Particularly from those

of individuals who may be less inclined to participate in traditional interviews or focus groups because they may not know what to verbalize in those instances and visual cues help to prompt discussion. Visual imagery can bridge language barriers and facilitate better communication between researchers and community members. It provides a common visual language that can enhance mutual understanding and collaboration, making the research process more effective and culturally sensitive. By moving beyond standard interview and focus group methods, researchers can collect more culturally relevant, inclusive, and rich data that can more clearly reflect the community's strengths and cultural heritage.

Strengths vs. Problems

Our research adds to the growing body of research that illustrates how design researchers can better incorporate participatory strengths-based approaches by engaging the community from the beginning, ensuring that the research is grounded in the community's strengths and priorities[111, 112, 118, 139]. All participatory approaches aim to help build trust and mutual respect, but incorporating culturally informed, strengths-based image searching into the ideation phase helped us to reinforce trust and respect with participants, which helped in the later co-design activities in our workshop series. While this paper focuses primarily on collecting perspectives on community strengths, our larger study also tackled the deficits in current practices of community research results dissemination in Alaska Native communities. In design session 2, participants focused on identifying the problems with current research dissemination practices in Alaska Native communities and iterated solutions to those problems. In session 3, they co-designed tools that incorporated community strengths with problem-solving for disseminating research results to Alaska Native communities. In these latter design sessions, participants frequently referred to the community strengths they shared during photo-elicitation activity in session 1, considering those community strengths to confront the problems with standard research practices in community-facing research results dissemination.

Developing research tools and methodologies that reflect and respect the cultural values and practices of the community is also crucial. Such approaches include using culturally

relevant symbols, languages, and narratives in the design of these tools. Taking a cue from asset-based design, conducting asset mapping to identify and document the community's strengths, resources, and successful practices helps shift the focus from deficits to assets and provides a foundation for building existing capacities[118]. Framing research findings in a way that highlights the community's strengths and successes, using positive narratives that celebrate resilience, adaptability, and cultural heritage, rather than focusing solely on challenges and problems, is essential to highlight supportive mechanisms in a community that can be useful to consider in addressing problems[111]. This isn't to say that deficits should be ignored but balanced with strengths-based perspectives. Collaborating with the community to co-create solutions that build on their strengths ensures that the solutions are much more culturally appropriate, sustainable, and supported by the community. By incorporating a strengths-based approach, design researchers can create more meaningful, respectful, and effective research outcomes, especially for marginalized communities[111, 112]. Such an approach not only enhances the quality of the research but also gives more power to the community by recognizing and building on their inherent assets and capacities. Moreover, using a strengths-based framework for data analysis adds value to support designing for community strengths and intrinsic values. We recommend that incorporating a strengths-based approach to how data are analyzed and incorporated into the design process supports a more comprehensive approach to incorporating community assets rather than traditional analytic approaches focused solely on identifying problems.

Limitations

Using Google Image Search for photo elicitation with Alaska Native community members in co-design may present several limitations. First, the images available through Google may not accurately represent the cultural context and lived experiences of marginalized communities, leading to potential misinterpretations and a lack of relevance[154]. Additionally, the search results might include stereotypical or biased representations that could reinforce harmful narratives rather than fostering genuine understanding and engagement. Another significant limitation is the potential lack of control over the quality

and authenticity of the images. These concerns are valid; however, our participants did not share with us that the images they selected from the search activity were not representative of their communities. As is evident by the images depicted in this paper, the images selected differed by Alaska Native cultural group and varied representative activities. Participants also shared personal insight on how the images they selected represented the concept (community, health and wellness, storytelling, and research) that the image search was meant to identify. The facilitator also asked participants if they had more specific search queries, they wanted the facilitator to conduct to better contextualize their perspectives. These additional search queries were done to get more specific search results (see Table 1). We chose to use Google Image Search for the activity for convenience and the variety of images available for participants to choose from. Other commercial stock photo image repositories we reviewed were more limited in the breadth of Alaska Native cultural groups represented and may be more likely to include stereotypical images of Alaska Native people or pan-Indigenous images as compared to what is publicly accessible on a platform like Google. Moreover, archival repositories are more likely to include historical images, and we wanted participants to also have access to images that depict Alaska Native people and practices as they currently exist in the present day. There may also be a chance that image search results include content that is triggering or traumatizing to participants. To help alleviate this, we restricted search content using Google's SafeSearch mode to filter potentially harmful images from search results. We also informed participants that they were welcome to step away at any time during the workshop activities if they felt uncomfortable for any reason. None of our participants did so during the activities.

Another limitation to this study is that it took place in an urban environment. Though many of the participants had experience living in rural areas in Alaska, they designed towards their current experiences of living in an urban setting. Although there are many Alaska Native people living in urban environments, those in rural communities may have differing perspectives and needs.

Conclusion

Our research highlights the profound resilience of the Alaska Native community, underscored by their integration of traditional knowledge, cultural practices, and values. By adopting a culturally informed image search activity into the co-design ideation phase, we have emphasized the community's inherent strengths, such as their commitment to cultural heritage, environmental stewardship, intergenerational knowledge, and adaptive practices. Incorporating HCI and design principles, we have provided an example of how culturally sensitive and inclusive research methodologies can further support and celebrate these strengths. This approach not only enhances the quality and impact of the research and ultimately, the design, but also empowers the community by recognizing and building on their unique capacities. Moving forward, design researchers must continue incorporating strengths rather than only considering deficits, ensuring that marginalized communities are respected, valued, and supported in more meaningful and sustainable ways. This approach would be one of many steps in the right direction towards better engaging historically marginalized communities.

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Chapter 6 Summary & Contributions

This chapter highlights an example of using a strengths-based research approach using collaborative photo elicitation to empower Alaska Native communities in design. It emphasizes shifting from deficit-focused to incorporating strengths-based research approaches to combat negative stereotypes and foster trust during the design process. Photo elicitation is used to explore cultural values and promote community resilience. The study employs a deductive qualitative approach to analyze data through resilience, socioecological, and sociocultural lenses. Additionally, it underscores the importance of community ownership and collaboration in research and design. This strengths-based approach aims to amplify cultural values and resilience within Alaska Native communities.

The key contributions of this chapter are:

- **Strengths-Based Research Approach**: I advocate for shifting from deficit-focused research to strengths-based methodologies when working with historically marginalized communities, such as Alaska Native people. This approach emphasizes resilience, cultural values, and community strengths, promoting epistemic justice and empowering narratives.
- **Photo Elicitation in Co-Design**: I demonstrate the use of photo elicitation as a tool for collaborative design ideation. By integrating culturally relevant image searches, the method helps participants recall and articulate cultural values, fostering deeper engagement and insights during the co-design process.
- **Cultural Representation in Design**: I highlight how visual imagery can amplify cultural strengths, such as storytelling, intergenerational knowledge sharing, and traditional practices, which were eventually incorporated into the prototype for health research dissemination tools participants co-designed.
- **Integration of Indigenous Epistemologies**: I underscore the importance of incorporating Indigenous knowledge systems and values into research methodologies, aligning with ethical frameworks that emphasize community ownership, collaboration, and cultural sensitivity.
- **Design Implications**: I inform Human-Computer Interaction (HCI) and design practices by showcasing how culturally sensitive and inclusive approaches can lead to more effective and respectful design solutions for marginalized communities.
- **Visual Imagery vs. Traditional Methods**: I highlight the advantages of using visual imagery over traditional interview methods, such as fostering engagement, capturing nuanced cultural information, and bridging communication barriers.
- **Balancing Strengths and Deficits**: I emphasize the need to balance strengths-based perspectives with problem-solving approaches in research and design, ensuring comprehensive and culturally relevant solutions.

These contributions advance user-centered design practices and provide a framework for conducting respectful and empowering research with ANAI communities.

Chapter 7: Enhancing Health Research Results Dissemination for Alaska Native and American Indian Communities through Indigenous Community-Centered Design

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Abstract

Alaska Native and American Indian (ANAI) communities not only face significant health disparities but are often underrepresented in health research dissemination. Existing communication tools may fail to effectively reach these communities in culturally relevant and accessible ways, limiting their ability to benefit from critical health research. We co-designed and evaluated a prototype for health research results dissemination for ANAI communities. We created and evaluated the prototype drawing from previous co-design workshops with ANAI people. 38 participants completed an evaluation providing feedback for further iteration and highlighting key features such as search functionality, ease of use, visual and interactive elements, and content accessibility. Participants emphasized the importance of community connection, educational resources, and personalized experiences. We feature an alternative design approach we call Indigenous Community-Centered Design to create more accessible and engaging health research communication tools for ANAI communities, fostering stronger connections and more accurate research representation.

Introduction

Developing effective health research dissemination tools for Alaska Native and American Indian (ANAI) communities is fundamental for enhancing community health and well-being. ANAI communities often face significant health disparities compared to the general United States population, including higher rates of chronic diseases, mental health issues, and substance abuse disorders[86]. Effective health research dissemination can help bridge these gaps by ensuring that significant health information reaches these communities in culturally and contextually appropriate and accessible manners. A key challenge is the historical context of mistrust towards research institutions. This mistrust stems from past unethical research practices and limitations on culturally and contextually sensitive approaches for research within ANAI communities[14]. Consequently, developing dissemination tools that are collaborative and culturally tailored is essential to build trust

and ensure the relevance and uptake of health information. Community collaborative research efforts, such as those involving participatory research models, have shown promise in improving the quality and relevance of health research for ANAI communities[155]. These models emphasize the importance of involving community members at all stages of the research process, from design to dissemination, thereby ensuring that the research better addresses the specific needs and contexts of the communities[156, 157]. Furthermore, effective dissemination tools can support ANAI communities by providing them with knowledge and resources to make informed health decisions. This empowerment is needed to promote health equity and improve overall community well-being.

In a previous study, we found that community norms around context, partnership, transparency, and dialogue were valuable considerations for developing interactive research dissemination systems for collaboration with ANAI communities[30]. Awareness of **context** includes researchers' understanding of local culture, including how to approach participants and show respect in culturally appropriate ways. This understanding may be achieved through **partnerships** focusing on power dynamics and regularly spending time with different stakeholder groups, many of whom may not be the design's intended end-user. **Transparency** is tied directly to clear communication which promotes more active **dialogue** providing a variety of ways to communicate that would not otherwise be possible (i.e., mixed multi-media)[30]. Based on this knowledge, we created and used a new approach, **Indigenous Community-Centered Design**. We piloted this approach through community participatory design workshops with ANAI community members to co-design a prototype for health research dissemination.

In this paper, we describe this new approach and the evaluation of our health research dissemination prototype that uses this unique design approach.

Background

Indigenous Community-Centered Design Approach

ANAI people have been conducting research long before Western empirical research methods were established. For example, before colonization and Russian acculturation, Unangax (Aleut) people in Alaska's Aleutian Islands had an elaborate calendar system that factored in the natural environment and when the natural environment and animals were at certain points such as, when birds are laying eggs or when seals are skinny from the winter. These systems identified the best times to go hunting and gathering for food[158]. It took exceptional observation and documentation aptitude to develop these systems of knowing. These methods considered the world around them and the connection between the social, physical, and spiritual worlds.

Yet, research is not always beneficial to ANAI communities and these communities have experienced a history of unethical health research conduct. This disreputable research has imposed stereotypes on Indigenous people and has historically benefitted individual researchers or specific research institutions instead of helping the communities where the research was conducted[1]. These discrepancies have led to an increase in standards for ANAI community collaboration and Tribal research sovereignty and solidarity in ANAI health research. Yet, limitations still indicate the need for new methods to attain more contextually focused strategies. We integrated a response to this unethical history into our study design and have developed a new approach that we term **Indigenous Community-Centered Design**. Our approach incorporates community-engaged research and an Indigenous research methodology of ***relationality***, with empirical user-centered design methods including participatory design, value-sensitive design, and speculative design.

Incorporating Relationality & Community Respect from Indigenous Research Methodologies

Indigenous research methodologies prioritize the relationships and interconnectedness between people and their physical, social, and spiritual environments[1]. This approach contrasts with positivist social science research methods which aim to predict and control

behavior[159]. By incorporating relationality into our design process, we are acknowledging that relationships, social or otherwise, shape how we engage with ANAI research participants and how we understand the data they share with us. In community-engaged research, ANAI community members are often engaged throughout the research process including conceptualizing research topics, developing research questions, collecting, analyzing, and interpreting data, and disseminating study results[8, 12-14]. As part of honoring relationality and community-engaged standards, we have followed established guidelines for conducting research with ANAI communities by including essential ANAI representation on our research team. Two of the authors (Dirks (*Unangax*) and BearBow (*Southern Cheyenne*)) are ANAI researchers. As an outcome of ANAI communities' rights for Tribal research sovereignty, community engagement in research is now overwhelmingly standard for conducting research with and for ANAI communities [11, 12, 160]. Moreover, multi-directional communication with communities is important to foster trust and to help ensure information shared and collected remains pertinent and meaningful to impacted communities[14-17]. For ANAI communities, the information must be pertinent to the local context, encompassing local values, knowledge, and expertise[18-20].

We also follow standards of respecting Tribal sovereignty towards research[160] and have received the proper Tribal health research review and approval to conduct this study with ANAI communities. Additionally, we take an asset-based approach to our research, wherein we recognize historical trauma and injustices while, at the same time, community wellbeing, Indigenous knowledge and culture, and community resiliency as protective factors for community wellness[160]. One way we have enacted this approach was to conduct our prototype user evaluations during the University of Washington (UW) First Nations Annual powwow, a cultural event that honors Tribal community members who participate in this cultural activity. Our research highlights community knowledge and strengths, viewing them as paramount to developing more useful and appropriate health research dissemination tools for ANAI communities.

Adapting Participatory Design Methods

User-centered design approaches, such as participatory design are potentially beneficial when exploring ANAI community research dissemination values. Participatory design seeks to democratize information technology use and innovation [25, 26]. Core tenets include giving stakeholders meaningful influence in design and providing mutual learning opportunities between researchers and stakeholders [27]. Ideally, effective design gives stakeholders the ability to share their critical feedback on design solutions, create insight into ideas and prototypes, and understand design phases and concepts[28].

Forming mutual trust is essential for maintaining participatory relationships. Without it, participants may not feel comfortable fully disclosing information for fear of retribution[56]. Trust building can occur through iterative reflection on community interpretations of technology, which may help uncover local frameworks to reference technology interaction that may be more sensible to community members than academic frameworks[59]. As part of our process, we were very open to community insight which led to making adaptations to our design activities to better meet needs and support trust building while providing an opportunity for participants to practice design activities before even moving forward with our intended design. Moreover, community participants should be able to openly express opinions about existing and proposed designs[28] as they may be less likely to share opinions if they distrust or misunderstand the design process or feel like they will be in trouble if they openly share. Pre-design activities intended to introduce design frameworks and stages can help develop an understanding of the participatory design process which may encourage trust[57, 58]. As part of our design process, we developed procedures to introduce the design process to participants prior to focusing on our intended design. This helped develop a sense of comfort with the design process and gave participants an opportunity to suggest changes to the process so that they were more open to sharing their insights.

Research that honors Indigenous knowledge while acknowledging researchers' learned biases towards what constitutes valid data is imperative for the conduct of ethical research and design with Indigenous communities. Our research encourages collaboration during the

research activities which, ideally, promotes respect and validity for all knowledge systems (e.g., Western and Indigenous). As each community has its unique characteristics, eliciting feedback from ANAI communities to provide direct response on how and in what ways they want to receive research results is imperative to make decisions on how technology should be used to disseminate research results to their communities.

Prototype Development

We followed this Indigenous Community-Centered Design approach to develop our prototype for disseminating health research results. The purpose of our co-design workshops was to design a tool that health researchers can use to share community-facing results of research conducted in ANAI communities. Our prototype was grounded in data collected with ANAI people in Anchorage, Alaska. Anchorage is an urban center, and as such, it includes diverse ANAI cultural representation. Because of this setting, workshop participants co-designed a tool that is representative of this diversity. Note that each community has its own specific values, priorities, and expectations, and our workshop participants highlighted what is focal to them. Other ANAI communities may hold different priorities, which makes it important to establish partnerships with specific communities to verify their unique needs.

We used thematic analysis[161] to identify our workshop participants' goals for a health research dissemination tool. Participants identified three main goals for the prototype: learning, communicating, and finding. They emphasized the importance of ***learning*** about research results while acknowledging the history of unethical research in ANAI communities. They also wanted access to relevant health education resources to support their wellbeing. For ***communication***, participants suggested integrating social features to facilitate discussions among stakeholders and with researchers. They also wanted to be able to easily ***find*** and track ongoing research in their communities and access resources to address research problems proactively. Thus, the prototype content should include **research education, research background, topical health resources, status of study, and study results,** with clear, straightforward language and cultural and contextual

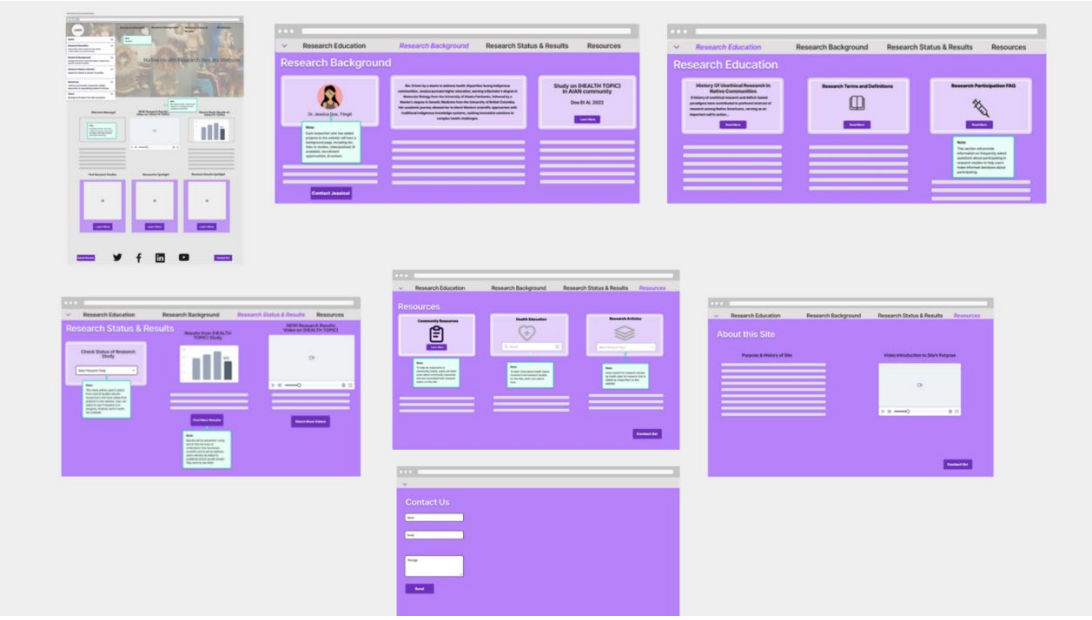
sensitivity. Workshop participants also shared that visual design elements should reflect diverse ANAI cultural backgrounds and activities to ensure representation and relevance.

Methods

We conducted a mixed-method evaluation of our low-fidelity prototype. Methods for our process and procedures for data collection and data analysis are provided in this section and include information about our data collection materials, study procedures, analysis, and ethical considerations.

Materials: Data collection materials used in this study included: (1) laminated handouts of the low-fidelity prototype (Figure 1) that we co-designed with ANAI participants and (2) a user evaluation survey. The prototype consisted of wireframes that illustrated the basic layout, design, and functionality of a website for disseminating health research in ANAI communities. We designed the evaluation survey to gather qualitative and quantitative feedback from participants. The purpose of this initial evaluation was to get feedback on the content and functionality of the prototype rather than visual design elements which will be included in a more interactive version to be developed in the future.

Figure 1. ANAI Research Prototype Wireframes (see also Appendix B)



Procedures: A randomized sampling strategy[95] was used to recruit participants to complete the usability evaluation survey during the University of Washington First Nations Annual Powwow—an annual Tribal event open to the public. Participants were recruited from a table outside of the powwow activities along with other vendors and organizations promoting their businesses. Inclusion criteria required participants to be 18 years or older and interested in both reviewing our prototype for health research results dissemination for ANAI communities and providing survey feedback. We provided participants with an overview of the study's purpose and procedures, and verbal consent was obtained from all participants before they began the prototype evaluation. Participants were voluntarily entered into a random drawing for a chance to win a prize (e.g. gift card, beaded earrings). They were then given access to the prototype and instructed to navigate through the various sections and features, exploring the prototype as they might with a fully functional website. After interacting with the prototype, participants completed the evaluation survey, which included a mix of closed-ended and open-ended questions designed to capture their impressions, preferences, and suggestions for improvement. Key areas of focus included search and accessibility features, content and information presentation, interactive and personalized features, and overall design and usability. Responses from the evaluation survey were collected and recorded for analysis, with both qualitative and quantitative data gathered to provide a comprehensive understanding of participant feedback.

Data analysis: Quantitative data from the closed-ended questions were analyzed using descriptive statistics to identify trends and patterns in participant responses. Qualitative data from the open-ended questions were analyzed using thematic analysis[161] to identify common themes and insights related to the prototype's design and content. We used R for quantitative analysis and Dedoose for qualitative analysis.

Ethical Considerations: This study was approved by the University of Washington Institutional Review Board and the Alaska Native Tribal Health Consortium’s Alaska Area Institutional Review Board. It was also approved by a Tribal health research review board.

Participants

The study included 38 participants with diverse demographics. The majority self-identified as American Indian or Alaska Native (68%, n=24), followed by White (15%, n=6), African American or Black (11%, n=4), and Asian (8%, n=3), while 18% self-identified as Hispanic (n=6). The gender distribution was predominantly female (76%, n=29), with male (13%, n=5), transgender (10%, n=3), and gender non-conforming (1%, n=1) participants also represented. Participants ranged in age from 21 to 55 years, with an average age of 36 (SD=11.7). Most participants had at least some college education (95%, n=32).

Results

Participants were asked to share feedback on the prototype concept, including understanding of the purpose of the prototype concept (*Table 1*), finding information (*Table 1*) and likelihood of use (*Table 2*).

Overall, most participants found the prototype concept to be effective in conveying the purpose of each prototype section (*M=3.86, SD=1.03, n=37*). They also found it easy to find information within the prototype (*M=4.12, SD=0.91, n=34*).

Table 1. Understanding prototype purpose and finding information

Question	N	Range	Minimum	Maximum	Mean	Std. Deviation
How well does the website draft concept share the purpose of each page? (*Scale: 1 not very well to 5 very well*)	37	4.00	1.00	5.00	3.8649	1.03178
How easy was it to find the information you were looking for in the different parts of the draft website pages? (*Scale: 1 not easy at all to 5 very easy*)	34	4.00	1.00	5.00	4.1176	0.91336

We also asked participants to share feedback on the likelihood of the prototype being useful to themselves and other specific groups (*Table 2*). Overall, the responses indicate that participants found the prototype concept to be useful across different groups, including

ANAI Youth (*M= 4.35, SD=0.98 n=34*), ANAI Elders (*M=4.41, SD=0.74, n=34*), and health researchers (*M=4.45, SD=0.94, n=33*). The likelihood of participants using the prototype once it is finished was also high (*M=4.48, SD=0.65, n=35*), reflecting strong interest and positive reception.

Table 2. Likelihood of Use

Question *(Scale: 1 not very likely to 5 very likely)*	**N**	**Range**	**Minimum**	**Maximum**	**Mean**	**Std. Deviation**
How likely or unlikely is a website like this to be useful to our ***Native Youth***?	34	3.00	2.00	5.00	4.3529	0.98110
How likely or unlikely is a website like this to be useful to our ***Native Elders***?	34	2.00	3.00	5.00	4.4118	0.74336
How likely or unlikely is a website like this to be useful to ***health researchers***?	33	3.00	2.00	5.00	4.4545	0.93845
How likely or unlikely would ***you*** be to use this website once it is finished?	35	3.00	2.00	5.00	4.4857	0.65849

Summaries of participant qualitative feedback are outlined below by use and functionality, visual attributes, interactive attributes, personalization, and contextual information (*see also table 3 for highlights*).

Use and Functionality

When asked about the use and functionality of the prototype, participants highlighted a range of features they valued. They liked the ability to discover ongoing and completed research studies in ANAI communities, to understand how research study results help solve problems for ANAI communities, to have the ability to send direct messages to researchers, and to post comments about the research through a comment forum. They appreciated the notion of a clear, well-organized, and straightforward layout, mentioning the systematic structure and ease of navigation. Most found it easy to understand, with clear sections, objectives, and consistent language. Participants valued the transparency in presenting research status, reports, and researcher bios, which helped them feel more informed and confident about the information available. Participants also noted that the potential for a

website tool like this stood out from others they've engaged with and could help users find necessary health research resources more effectively. Accessibility features, such as high contrast colors and easy-to-read text, were valued, especially for the possible use by ANAI Elders, and hover-over pop-ups for definitions and instructions were also noted as potentially useful.

Visual Attributes

Although our prototype evaluation was intended to be less on the prototype's visual attributes and more on its content functionality, and information organization, many participants responded to its visual appeal. Many valued the simple layout, which featured easy-to-understand graphics and high contrast for better accessibility. The simple, clean, and user-friendly design made a strong impression, with some participants specifically highlighting the front page, use of Indigenous images, and color schemes. However, some participants described the visuals as "dull" and "basic," and suggested including more graphics, infographics, and vibrant colors, particularly to engage younger users. They also suggested adding more creative polish, making the website less "square and gray", and including regional or Tribal maps to aid in navigation to information on specific communities. They emphasized the need for more Indigenous images, graphics, and art/design elements in negative space, suggesting enhancements with more interactive graphics. To appeal to a broader audience, some recommended using larger text and diverse fonts. Specific requests included ensuring that the "Home" dropdown menu uses varied synonyms instead of repetitive headers for increased clarity which is contrary to established user experience standards.

Interactive Attributes

Participants found the ability to check research status and view results in different media formats (e.g. video, text) memorable. They noted including videos on each page to break down dense research information was positive. Researcher bios and photos made the site feel more personal and relatable. Pages dedicated to community health resources and background information about research and ethical protections were also important

features. However, some participants indicated a need for additional interactive features to enhance understanding and usability. Some participants suggested adding more robust search features to allow users to search by researcher's name, Tribe, geographic location, and health research topic, highlighting these features as having positive impacts on search and accessibility. Adding a site map and making the navigation more user-friendly were recommended, as well as a dedicated page about the organization managing the research and its members. They also expressed interest in engaging with more multimedia content, such as listening to podcasts about research study results and accessing educational tools like research-related certification courses and self-assisted learning materials. A few participants emphasized the importance of integrating social media features, such as hashtags and social media posts, to enhance engagement and connectivity to information across social media platforms.

Personalization

Participants suggested personalized features, such as forums for comments and discussions, and noted the potential for personalizing their experience through more curated content or favorites. They understood and appreciated the prototype's purpose of sharing health research results with ANAI communities and valued the potential to connect with researchers and other community members. Elements like an interactive map to select different ANAI groups and options for users to choose colors and graphics were suggested, along with making the website multilingual to improve accessibility. Participants also recommended personalizing user pages post-signup including features that allow users to see curated content based on their preferences such as a feature to "favorite" specific studies, researchers, communities, or health topics for curated updates.

Contextual Information

Some participants also wanted more information about research participants and the overall research in more simplified terms. Some participants also requested simplified examples of research topics and more information about how data is gathered and used.

Some also felt the prototype structure was good and only needed minor tweaks, expressing satisfaction and eagerness to see the next version. Despite these suggestions, several participants mentioned there was nothing they particularly disliked about the prototype concept.

Table 3. Highlights of Qualitative Feedback by Theme

Theme	Key Feedback
Use and Functionality	➢ Communication platform o Direct messaging o Social media integration ➢ Understandability of research ➢ Accessibility features ➢ Promote research transparency o Research study information o Research results o Researcher information
Visual Attributes	➢ User-friendly design ➢ Graphics, infographics, Indigenous representation ➢ Fonts and color
Interactive Attributes	➢ Varied multimedia options o Video, text, images o Podcasts o Educational Tools o Social Media ➢ Interactive maps ➢ Search features
Personalization	➢ Forums for discussion ➢ Curated content ➢ Control of user settings
Contextual Information	➢ More information about research participants and processes ➢ Simplified terms

These suggestions reflect a desire for a visually appealing, interactive, and user-friendly tool that offers robust search capabilities, personalized content, and clear, accessible information. These insights underscore participants' desires for a visual tool that effectively

communicates health research results and fosters community engagement as well as education.

Implications

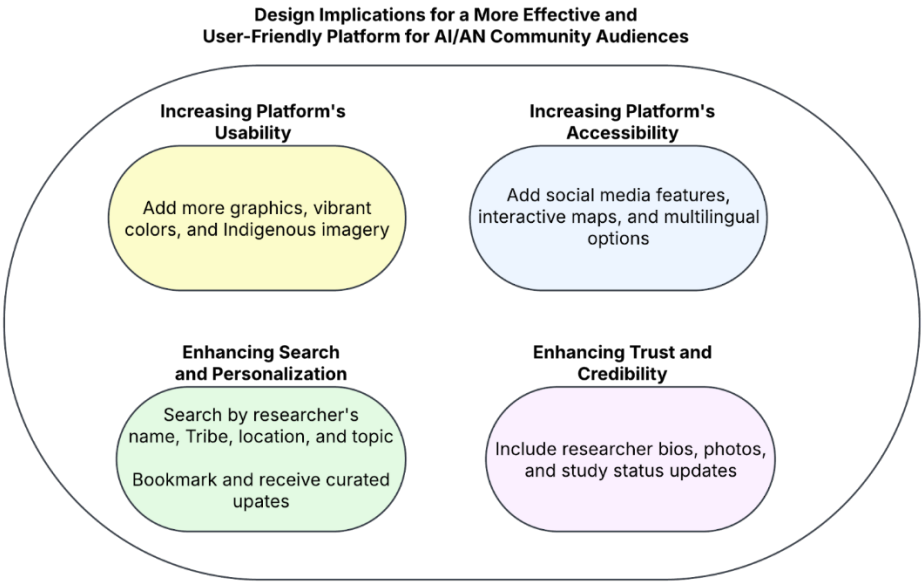
Our Indigenous Community-Centered Design approach not only supports to enhance our prototype's visual appeal and functionality but also honors Indigenous community knowledge and methodologies. It fosters trust, engagement, and collaboration, ensuring that the platform is both more effective and more culturally and contextually appropriate for ANAI communities. The feedback gathered from participants on our prototype evaluation provides valuable insights for the development of a more effective and user-friendly research results dissemination platform for ANAI community audience (Figure 2). The emphasis on visual appeal, accessibility, and interactive features highlights the importance of designing a tool that is not only informative but also engaging and easy to navigate. On a surface level, incorporating more graphics, vibrant colors, and Indigenous images could enhance the visual appeal and make the website more attractive to a broader audience, including younger users.

On a more technical level, the need for robust search functionality and personalized content underscores the importance of providing users with tools to easily find and engage with relevant information. Features such as the ability to search by researcher's name, Tribe, geographic location, and topic, as well as the option to favorite specific studies and receive curated updates, can significantly improve user experience and satisfaction. The feedback also indicates a strong desire for social media integration and interactive elements, which can increase accessibility and foster greater engagement and connectivity among users. Integrating social media features, such as hashtags and posts, and adding interactive elements like maps and multilingual options can enhance functionality and appeal. Participants value being able to connect with one another and have an ability to respond and communicate about research being conducted in ANAI communities in a convenient way.

The ethical importance of content transparency and the inclusion of researcher bios and photos suggest that users value a personal and relatable connection to the research being

presented. Offering clear, accessible information about research status, reports, and the researchers involved can help build more trust and confidence in the platform. Moreover, providing a platform for community members to easily communicate with both researchers and other interested users supports increased transparency and collaborative processes that are less commonly used in standard research dissemination methods.

Figure 2. Design Implications (Credit: designed by Hyeyoung Ryu)



Conclusion

These insights highlight the need for a comprehensive, community-centered, and user-centered approach to the design and development of health research dissemination tools for ANAI communities. By addressing the identified improvement areas and incorporating suggested features, developers can create effective tools that not only communicate health research results but also foster community engagement and education, leading to a more equitable and supportive environment focused on community strengths and relationships. Additionally, this approach ensures that the tools are more culturally resonant and respectful of Indigenous knowledge systems, promoting trust and collaboration between researchers and ANAI communities. By integrating community feedback and prioritizing relationality, we can develop platforms that are not only informative but also affirming of

community perspectives and needs, ultimately contributing to the overall well-being and resilience of ANAI communities.

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Chapter 7 Summary & Contributions

This chapter discusses the evaluation of the prototype for disseminating health research results tailored to ANAI communities using the Indigenous Community-Centered Design approach I developed for this research. In this study, I underscore the importance of culturally resonant tools that honor Indigenous knowledge systems, foster trust, and promote community engagement. I advocate for a comprehensive, community-centered approach to health research dissemination, using Indigenous Community-Centered Design, aiming to improve health equity and well-being in ANAI communities. The prototype was evaluated by 38 participants during the University of Washington First Nations Annual Powwow. Evaluation feedback highlighted the importance of search functionality, accessibility features, interactive elements, and personalized experiences. Participants appreciated the prototype's transparency, ease of navigation, and potential for fostering community connections. Participants found the prototype useful for ANAI Youth, Elders, and health researchers, with high likelihood to use a future model. Suggestions for

improvement included enhancing visual appeal, adding interactive features (e.g., multimedia content, social media integration), and providing personalized options like curated content and multilingual support.

The key contributions of this chapter are as follows:

1. **Introduction of Indigenous Community-Centered Design**: I introduce a design approach that integrates Indigenous research methodologies, relationality, and user-centered design principles. This approach prioritizes cultural relevance, community collaboration, and respect for Tribal sovereignty in health research and user-centered design.
2. **Evaluation Insights**: The study provides valuable feedback from 38 participants, identifying key features such as search functionality, interactive elements, personalized experiences, and accessibility improvements. It also highlights the importance of visual appeal and multimedia content.
3. **Implications for Health Equity**: By addressing cultural and contextual needs, the study contributes to the development of tools that promote health equity, community engagement, and health education in ANAI communities.
4. **Framework for Future Research**: The findings and design approach provide a framework for creating culturally resonant health research dissemination and communication tools for other Indigenous communities, emphasizing relationality and community strengths.

These contributions collectively advance the field of health informatics by offering a culturally sensitive, community-driven model and health research dissemination and communication tool that emphasizes the unique needs of ANAI communities.

Chapter 8: Conclusions

In this final chapter, I provide an overview of how my study findings fulfilled each of the dissertation aims I introduced in Chapter 1. I then provide a summary of my contributions, discuss the limitations of my studies, and share opportunities for future research.

Overview of Aims

Aim 1: Define ANAI stakeholder values for collaborative health research results dissemination. In chapter 4, I shared how I used a value-sensitive design framework to conduct co-design workshops with 6 participants to explore ANAI stakeholders' values for research collaboration in general and for health research results dissemination. Key findings from this study highlight the need for culturally responsive approaches that respect local norms, power dynamics, and diverse communication methods. I advocate for co-designing technology systems that integrate Indigenous epistemologies to enhance trust, communication, and adoption of research outcomes. I also developed a value-based conceptual framework for ANAI health research results dissemination. The conceptual framework emphasizes community partnership, community context, transparency, and dialogue and was used to scaffold all co-design data collection activity for Aim 2.

Aim 2a: Co-Design an ANAI culturally responsive prototype for collaborative health research results dissemination and communication. In chapter 5, I share how I used participatory design and speculative design to co-design a technology dissemination communication tool with ANAI people. The study involved three co-design workshop sessions with 12 ANAI community participants in Anchorage, Alaska. The workshops introduced concepts of health research dissemination, storytelling, and health and wellbeing, culminating in the co-design of a research results dissemination website prototype. In chapter 5, I share a summary of thematic analysis that was used to develop the prototype. The prototype was developed after compiling results from thematic analysis. Analysis focused on user needs, pain points, design preferences, and functionality. Analysis revealed that participant goals for the prototype were to learn, communicate, and find information. Content design features that participants wanted included: research education

(e.g., glossary, history of unethical research), research background (e.g., researcher bios, funding sources), resources (e.g., health education, peer-reviewed articles), research status and results (e.g., infographics, podcasts), and communication tools (e.g., comment sections, social media integration). Visual design features included cultural representation through, color, symbolism, and activities such as Native dance, drumming, and storytelling.

In chapter 6, I delve a little deeper into the co-design process, describing how a strengths-based approach was used in both the research design and analysis of workshop data. I emphasize shifting from deficit-focused to incorporating strengths-based research approaches to combat negative stereotypes and foster trust during the design process. Photo elicitation is used to explore cultural values and promote community resilience. I used a deductive qualitative approach to analyze photo elicitation data through resilience, socioecological, and sociocultural lenses. Additionally, I underscore the importance of community collaboration in research and design. The strengths-based approach I used aims to amplify cultural values and assets within ANAI communities. I also highlight the advantages of using visual imagery over traditional interview methods, such as fostering engagement, capturing nuanced cultural information, and bridging communication barriers.

Aim 2b: Develop and evaluate prototype feasibility and acceptability in an ANAI community-based setting. In chapter 7, I discuss the evaluation of the prototype and share information about the Indigenous Community-Centered Design approach I developed and used in all study aims. I advocate for a comprehensive, community-centered approach to health research dissemination, using Indigenous Community-Centered Design, aiming to improve health equity and well-being in ANAI communities. The prototype was evaluated by 38 diverse participants during the University of Washington First Nations Annual Powwow. Evaluation feedback highlighted the importance of search functionality, accessibility features, interactive elements, and personalized experiences. Participants appreciated the prototype's transparency, ease of navigation, and potential for fostering community and researcher connections. Participants found the prototype potentially useful for ANAI Youth, Elders, and health researchers, with high likelihood to use a future model. Suggestions for improvement included enhancing visual appeal, adding interactive features (e.g.,

multimedia content, social media integration), and providing personalized options like curated content and multilingual support.

Key Contributions

Though I have shared contributions of my research at the end of each chapter, I will highlight the most prominent contributions here. The key contributions of this dissertation are multifaceted, encompassing, theoretical, methodological, empirical, and practical advancements in ANAI health research results dissemination and user-centered design.

Indigenous Community-Centered Design

My research highlights the significance of placing ANAI communities at the center of health research design. By prioritizing their knowledge, experiences, and cultural contexts, my studies foster more relevant and respectful research and design practices. I underscore the importance of incorporating Indigenous knowledge systems and values into research methodologies, aligning with Indigenous research ethical frameworks that emphasize community ownership, collaboration, and cultural sensitivity. I also inform Human-Computer Interaction (HCI) and design practices by showcasing how culturally sensitive and inclusive approaches can lead to more effective and respectful design solutions for marginalized communities. The findings and design approach provide a framework for creating culturally resonant health dissemination and communication tools for other Indigenous communities, emphasizing relationality and community strengths.

Strengths-Based Methods

The incorporation of strengths-based methods in my research underscores the value of recognizing and leveraging the inherent strengths within ANAI communities. This approach not only empowers communities but also enhances the quality and impact of research. I provide an example of its use and add to the growing body of research on asset-based design.

Conceptual Framework

I contribute a value-based conceptual framework for technology-facilitated collaborative dissemination tailored to ANAI contexts. Future research using the community research dissemination framework to other disciplines would be appropriate, possibly considering differences in quantitative versus qualitative research methods across physical science, social science, and information science domains and within various historically excluded community contexts.

Prototype for Health Research Results Dissemination

The prototype I developed provides a model for designing a fully operational system for research communication, collaboration, and education that is grounded in ANAI community perspectives.

Limitations/Future Work

While my dissertation provides valuable insights and contributions, there are, of course, some limitations that must be acknowledged, along with directions for future research:

Evaluation

Additional evaluation is necessary to assess the long-term impact and sustainability of both the prototype concept and the co-design activities.

The prototype was evaluated with only 38 people. A more extensive user test with more participants could increase our understanding of the prototype's usability and acceptability. Although many of these participants were ANAI, not all of them were. Moreover, most of the participants had at least a college education. It would have also been beneficial to evaluate the prototype with health researchers. Additional studies should include evaluations with more stakeholder groups.

I intended on conducting participant evaluations after each co-design activity to measure satisfaction, power relationships, and acceptability of design activity. Adding another data collection activity to my design sessions was not feasible as it would have extended the time involvement. Future studies would benefit from adding a systematic evaluation component

to measure ANAI participants acceptability, power dynamics, and satisfaction for participatory design activities. Future studies should incorporate comprehensive evaluation frameworks to better understand their experiences with participatory design. Furthermore, the Indigenous Community-Centered Design approach needs additional evaluation to further explore its feasibility and acceptability.

Village Settings

Rural village communities have very different contexts compared to urban communities. Although many of my participants had experience living in village communities and spoke to some of that experience in our design sessions, they lived in an urban setting at the time of data collection. Future research should expand to include a broader range of rural communities to ensure findings are more relevant to their contexts.

Higher Fidelity

Higher fidelity in the application of strengths-based methods and Indigenous community-centered design is needed. Future work should focus on refining these approaches to better understand their implementation and effectiveness. Moreover, a higher fidelity prototype should also be evaluated. My research included an evaluation of low-fidelity wireframes. More research is needed to test a fully operational technological prototype.

Disseminating Results

Research results were not disseminated to the community as timely as I wanted them to be. I plan to share research results with community participants and other key stakeholders in a variety of ways. First, I will use the prototype I developed for this research to share the results of my studies. I have already created a higher-fidelity prototype considering feedback from prototype evaluation that I will populate with information from my studies. Next, I will share written research results with Tribal leadership at Southcentral Foundation and the Alaska Area Institutional Review Board. Finally, I will share research results with academic communities through conference presentations and peer-reviewed manuscripts.

Collaborative Research Storytelling

The concept of collaborative research storytelling emerged as a powerful tool for disseminating research findings in my studies. Though I had originally planned on integrating digital storytelling as part of my design process, I came to realize that the research questions around storytelling were much bigger than what I could accomplish in my dissertation research. Future research should explore this approach further, examining its potential to enhance engagement and understanding among diverse stakeholders. One such study I plan to pursue involves an interdisciplinary collaboration with science communicators, artists, researchers, and members of Indigenous communities to explore collaborative research storytelling exploring questions surrounding the nature of collaborative storytelling, the roles of various stakeholders, and the vital aspect of knowledge translation to the process.

By addressing these limitations and pursuing future research directions, the research can continue to evolve, ensuring that both design approaches and health research information and communication are more inclusive, equitable, and impactful for ANAI communities.

Concluding Statement

In this dissertation, I aimed to explore and implement a strengths-based Indigenous Community-Centered Design approach to health research results dissemination with and for ANAI communities. By focusing on the perspectives and voices of ANAI communities, I sought to shift power dynamics, promote health information equity, and challenge standard research results dissemination practices. The findings and contributions of this research align with these objectives, demonstrating the effectiveness and importance of inclusive, community-driven approaches.

It is my hope that this research will support improvements of research communication and improve trust in health research in ANAI communities. This will then improve the impact of health research overall by ensuring that research outcomes are more effectively disseminated to ANAI communities. This will support our communities in understanding

research, potentially incorporating research recommendations and increasing support for using technology tools for research communication and collaboration.

This research also builds connections between researchers and ANAI communities urging further participatory design collaborations. The conceptual framework, approaches and methodologies, and prototype resulting from this research may also be applied to other communities historically marginalized by research who have experienced similar injustices which may have caused distrust for research, concerns over power dynamics, or faced biases because of results dissemination activities.

In a time when there is so much information available to us, there are also many more opportunities to misunderstand or misinterpret health research. We have seen this most prominently during the COVID-19 pandemic, where rampant health misinformation was spread, and in some cases, is still being spread. This was partially facilitated by people misunderstanding research or misusing information to fit their particularly narratives. In addition to providing a tool for disseminating research, my research findings promote more active communication between researchers and community audiences to help improve research understanding which can act as a mechanism to decrease the likelihood of perpetuating health mis- and dis-information.

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Appendices

Appendix A Wireframe Prototype

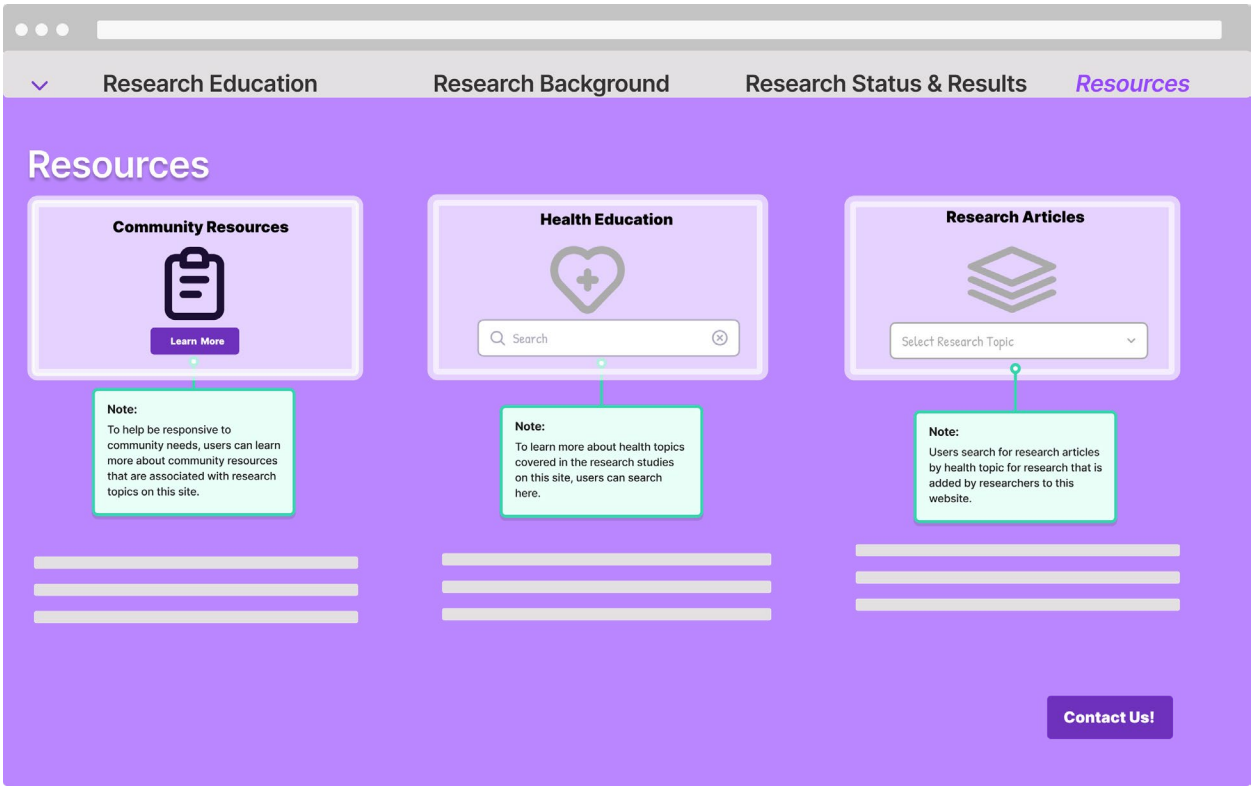
Prototype Homepage

Research Education Tab

Research Background Tab

Research Status and Results Tab

Resources Tab



Contact Tab

About Tab