

# Forging a new legacy of trust in research with Alaska Native college students using CBPR

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**Objectives.** Disparities in the rates of matriculation and graduation are of concern to Alaska Native (AN) students and the universities committed to their academic success. Efforts to reduce attrition require a keen understanding of the factors that impact quality of life (QOL) at college. Yet, a long-standing legacy of mistrust towards research poses challenges to conducting inquiry among AN students. We introduced a partnership between the University of Alaska Fairbank's Rural Student Services (RSS) and the Center for Alaska Native Health Research (CANHR) within which we conducted the "What makes life good?" study aimed towards developing a QOL measure for AN students. Equally important was building a legacy of research trust among AN partners.

**Study design.** We describe Phase I of a 2-phase study that employed a sequential mixed methods approach. Discussed are facilitators, challenges and lessons learned while striving to adhere to the principles of community-based participatory research (CBPR).

**Methods.** Phase I included formative focus groups and QOL measurement development. The research involved the interplay among activities that were co-developed with the goal of enhancing trust and research capacity. Emphasis was placed on ensuring that data collection and analyses were student driven.

**Conclusions.** All partners resided at the same university. However, trust and collaboration could not be assumed. Working within a collaborative framework, our partnership achieved the aim of developing a culturally informed QOL measure, while also creating an empowering experience for all partners who became co-investigators in a process that might normally be regarded with mistrust.

Keywords: *Community-based participatory research (CBPR); Alaska Native; quality of life; college students*

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University education poses challenges for Alaska Native (AN) students, especially students from remote and rural areas, as they experience marked differences between the values and customs at the college campus to that of their home community (1). For many students, these cultural incongruities and other challenges continue throughout their college experience, impacting their capacity to persist and achieve academic success (1–3).

Increasing AN student persistence towards graduation is a key goal of the University of Alaska Fairbanks (UAF) (4). Efforts to reduce attrition require a keen understanding of the factors that impact AN students' quality of life (QOL) at college. Yet, a long-standing legacy of mistrust towards Western and academic-based

research poses challenges to systematic inquiry required to inform culturally responsive interventions.

Here, we describe a collaborative research programme with AN college students. While the tangible goal was to develop a culturally grounded QOL measure, what emerged as equally important was building a new legacy of trust in research among AN partners.

## Background

AN students endure a wide disparity between their rates of enrolment and degree completion (5). This is of particular concern at UAF, where AN students experience significantly higher attrition rates when compared with their non-native peers (4). At the core of UAF's mission to "promote academic excellence, student success

and lifelong learning” (4) is the quest to serve all Alaskans, with an emphasis on providing educational opportunities to AN and rural students (4). As an open admission institution, the objective is not only enrolment of rural and AN students but also successful degree achievement.

### **The community–academic partnership – forged within an academic setting**

The 2 entities devoted to this collaborative research with AN college students are the UAF’s Department of Rural Student Services (RSS) and the Center for Alaska Native Health Research (CANHR). Although both reside at UAF, within this community–academic collaboration, RSS represented the community partner and CAHR the academic partner.

CANHR is a centre for biomedical research excellence funded by the National Institutes of Health. CANHR’s mission of “Building relationships and research-based knowledge to improve the health of AN people” (6) reflects the Centre’s commitment to research based within a framework of community-based participatory research (CBPR) (7–9). RSS strives to serve AN and other rural students who aspire to complete their college education. RSS’ mission is to respond to students’ needs and help them maintain academic, personal and cultural balance as they pursue higher education (10).

To assist rural students’ transition from high school to college, UAF offers several bridging programmes, such as the Rural Alaska Honors Institute (RAHI) (11). Yet, research reveals that college-based experiences, once students are enrolled in college, play a decisive role in their ability to thrive and persist as college students (12). Therefore, of equal or greater importance are the experiences of AN students already immersed in life at the university. Yet, little is known about the factors that impact AN students’ decision to continue their college education through to graduation (12).

Development of an AN college student QOL measure was originally conceptualised by CANHR researchers who proposed the idea to RSS. Particularly appealing was the prospect of conducting research that adhered to the CBPR principles, developed by Israel and colleagues (9), which would facilitate co-learning, capacity building and equity among all partners.

To achieve RSS’ mission to promote AN students’ college success, the information gained from a QOL measure could help inform initiatives and advocacy tailored to the strengths and issues defined by AN students, themselves. In discussing the research collaboration, RSS cautioned that many AN students held misgivings about participating in research activities, even those studies conducted within their own academic institution.

### **The call for community-based participatory research with Alaska Native students**

Progress has been made in conducting successful and respectful research with Alaska Native people (13). Nevertheless, a long-standing mistrust of research endures (7,14–16). This mistrust stems, in part, from highly publicised experiences, such as the 1979 Barrow Alcohol Study (17–19), during which individuals and entire communities were subjected to research practices that violated their privacy, disrespected their culture and cultural identity (14,16), and caused stigmatising harm when results were disseminated in a manner that portrayed participants and communities in a negative light (20).

Particularly viewed with scepticism is what many indigenous communities refer to as “helicopter research” (21,22). The reference is directed towards researchers who “fly” into the tribal community, collect their data with the least possible interaction and consultation with community members and then (after this intrusion) fly away never to be heard from again. The legacy of this approach is the suspicion that research will profit solely the investigator while no benefit will befall the community (17,20,22,23).

Mistrust among AN people towards research has been engendered not only by first-hand experiences with a culturally inappropriate researcher process but is also depicted within the stories and lessons passed down from generation to generation. RSS Director, Mekiana, shared her own story:

Growing up in an AN rural community it was always the underlying feeling when a stranger entered the community talking about research that it was best to stay away in order to stay safe. This perception of research related to being ‘not safe’ comes from one of the researches that was done on the community members of Anaktuvuk Pass. In the 1950’s several members were injected with Iodine 131 as part of military research on people in the arctic and cold weather adaptation. Community members shared their recollection of the events at a town meeting. It was discovered that community members were under the impression that they were going to be given an injection for the benefit of their health and not as a research subject matter. This and other similar stories have been passed down from generation to generation reinforcing the feelings of mistrust among ANs towards Western research and researchers.

This mistrust is also perpetuated within the academic setting, where the college campus can be characterised as a microcosm of “helicopter research”. For example, university-based studies often tap an accessible pool of undergraduate students as research participants (24,25). Similarities can be drawn to research conducted with remote and rural communities that might be considered

a “captive population” who are offered limited autonomy and virtually no access to research findings (24,25). For AN students, requests or course-based requirements to participate in research activities can create apprehension. One student expressed her reservations about being a research participant:

Being an AN, I seem to have more opportunities to participate in research than many of my non-native peers. I initially didn't mind, but it's starting to get old. The more I learn about the research process, the more wary I become. I've learned that despite advertising a specific purpose for a study, researchers often discover other findings and report on those instead. I wonder about the ethics of this kind of practice. Typically students who volunteer for a study get some sort of compensation (extra credit, cash), which is appealing to me, but it's not enough anymore. Participating in a study where the AN population could be portrayed in a negative light isn't worth it for me.

**Research integrity and oversight**

Each year, RSS receives multiple requests from researchers to facilitate access to AN students for their studies. In response, and in addition to academic advising, RSS takes responsibility as an “informal research gatekeeper”

to the community of AN students. As with other marginalised groups, AN communities often find themselves as the victims of everyone else's “great intentions” (26). This is no different for AN college students. As “gatekeepers”, RSS is wary that their students could be coerced, exploited or stigmatised as a result of their research participation. In turn, RSS was interested in promoting ethical research with AN college students; particularly research that would engage students from beginning to end.

**The study**

The “What Makes Life Good” Project was a 2-phase study employing a sequential, mixed methods approach that was entirely developed within the RSS and CANHR partnership (27,28). Phase I included a formative focus group process and QOL measurement development. Phase II comprised measurement implementation and validity testing. Here, we focus specifically on describing the processes used, lessons learned and challenges faced in co-conducting Phase I, which represented a cyclical interplay among project components that included trust-building, project development, capacity building, data collection and analysis, measurement creation and member checking. As shown in Table I, Phase I involved diverse activities to promote and

Table I. “What Makes Life Good?” Study Phase I: components and activities

Component	Collaborative activities
Trust building	<ul style="list-style-type: none"> <li>● Constant communication via:                             <ul style="list-style-type: none"> <li>○ scheduled meetings and impromptu visits at RSS</li> <li>○ email updates and check-ins</li> </ul> </li> <li>● Engagement in community and campus activities</li> </ul>
Project development	<ul style="list-style-type: none"> <li>● Project meetings and workgroups to:                             <ul style="list-style-type: none"> <li>○ inform project logistics and methods</li> <li>○ create and pilot-test materials and processes</li> </ul> </li> </ul>
Capacity building	<ul style="list-style-type: none"> <li>● Opportunities for student involvement included:                             <ul style="list-style-type: none"> <li>○ open planning meetings</li> <li>○ pre-study focus group workshop</li> <li>○ interactive focus groups<sup>(1-2)</sup></li> <li>○ post-focus group workgroup sessions<sup>3</sup></li> </ul> </li> </ul>
Data collection and analysis	<ul style="list-style-type: none"> <li>● Interactive focus group processes:                             <ul style="list-style-type: none"> <li>○ word association activity<sup>1</sup></li> <li>○ all on the wall activity<sup>2</sup></li> </ul> </li> </ul>
Measurement creation	<ul style="list-style-type: none"> <li>● Post-focus group workgroup sessions</li> </ul>
Member checking	<ul style="list-style-type: none"> <li>● Post-focus group workgroup sessions</li> <li>● Interactive findings forum<sup>4</sup></li> </ul>

<sup>1</sup>Word association activity: On sheets of flipchart paper, students shared words/phrases they associated with “Life”, “Quality” and “Quality of Life”.

<sup>2</sup>All on the wall activity: Independently, students listed (on sticky-notes) factors that contribute to their QOL at college. Students shared their notes and posted them on a blank wall. Students worked together to group the factors into conceptual domains (29).

<sup>3</sup>Post-focus group workgroup sessions: Students and researchers synthesised focus group findings and developed draft QOL survey.

<sup>4</sup>Interactive findings forum: Students, RSS staff and researchers gathered to discuss focus group findings and provide feedback about the draft QOL survey (30).

strengthen the collaborative project and to maximise inclusion and participation.

As revealed in Table I, emphasis was placed on ensuring that students took the lead in driving all data collection and data analysis activities. As such, focus groups involved a word-association activity, which prepared students to consider the factors that contributed to their QOL at college, and an all on the wall activity (29), which enabled students to explore, share and group the factors that impact their QOL into thematic domains. During post-focus group workgroup sessions, researchers and students further interpreted and synthesised the QOL themes that emerged across the 6 focus groups. From this collaborative analysis, they developed a draft QOL measure for review during the interactive findings forum that was hosted at the completion of Phase I (30).

### Value and challenges encountered in applying principles of CBPR

Here we discuss insights and lessons learned while conducting the collaborative activities (listed in Table I) within a CBPR framework that emphasised community identity, strengths and assets, co-learning, collaboration, and mutual benefit (8,9).

#### *Recognise community as a unit of identity*

Despite the great diversity they represent, AN college students embody a cohesive community with similar experiences of culture, traditions, values and beliefs (22). One common experience for students is that of navigating between 2 worlds; an undertaking that requires strategies and decision-making as to when and how one abides by either or both native and Western ways (22). Working in collaboration facilitated a research process that enabled students to discuss and reflect upon this cultural duality. Per this reflection, students explored their QOL against the social, political, historical and geographical backdrop of identifying as ‘AN’, while also adapting to a western-dominated college environment (12,13). For example, during the all on the wall activity, students openly shared experiences when their native values (often revolved around family and community well-being) were in distinct conflict with expectations of university scholarship (often affording priority to individual achievement).

#### *Build on community strengths and resources, and address health from positive and ecological perspectives*

A key factor in RSS’s decision to collaborate in this study was the project’s strengths-based emphasis. By providing the opportunity for students to explore the things that make life “good”, they identified the power and strength that could be harnessed to enhance QOL rather than solely highlighting what needs to be “fixed” for AN students (16).

While the study focused on assets, understanding the barriers to QOL was also important. In maintaining a strengths-based approach, the challenge was to develop a sensitive process for exploring QOL obstacles. Our process of identifying, discussing and grouping those factors that make life good provided a natural segue for students to further discuss factors that might make it difficult for them and other students to achieve QOL. This discussion of barriers enhanced understanding by all partners of the complex nature of QOL, and how both individual-level (personal motivation) and social-level influences (micro-aggression and financial issues) impact well-being of AN students (16). In discussing both the positive and negative factors, students offered viable solutions to challenges that were grounded in strengths they identified within themselves and the QOL themes they generated.

#### *Promote co-learning*

Prior to conducting the focus groups, we offered a focus group workshop. Providing the workshop helped to ensure that partners and participants fully understood what the project would entail. The workshop also set the stage for several students to become active and critical co-investigators throughout the research process. In fact, 1 student who attended the workshop not only participated in a focus group but also volunteered to take notes during subsequent focus groups. Based on her interest, commitment and enthusiasm, she was eventually hired as a paid research assistant. She is a co-author on this manuscript.

While a key aspect of community–academic partnership involves determining what expertise and responsibilities each partner will bring to the table, we found that our roles needed to remain fluid and flexible (31). For example, CANHR researchers took primary responsibility for developing the focus group workshop. To set the stage for discussing focus groups within a cultural context, student participants were asked to reflect on the similarities and differences between focus groups and talking circles (an egalitarian method frequently used in native communities to facilitate group discussion) (32). Yet, discussion revealed that most students were either unfamiliar with talking circles or that they saw their use in research as a signal that White researchers’ were trying to make Western research and interventions seem more “Native”.

Although this misstep could have led to disaster in terms of building rapport and credibility between the researchers and students, the discussion actually served to establish trust. Demonstrated was the humbled researchers’ openness to listen and learn from the students and the students’ willingness to share their cultural knowledge. In forging trust, the door was ajar for students and researchers to share co-ownership of the project.

In addition to the workshop, co-learning and capacity building were integrated into all project-related activities. Several students accepted opportunities to be involved in focus group facilitation, data analysis workgroups and QOL measurement development activities.

Opportunities for capacity building further ensued as RSS staff and CANHR researchers navigated their new collaborative relationship. This capacity was extended to other CANHR researchers when the RSS Director, Mekiana, was invited by the Director of CANHR to speak during an investigators' meeting about culturally respectful ways to collaborate with RSS and its student population.

### *Facilitate collaboration across all phases of the research*

An early highlight of our project was an introductory meeting that brought to the table RSS staff, 2 AN college students and 2 CANHR researchers. The goal of this initial meeting was to discuss the QOL project and to begin informing various methodological and logistical aspects of the research process.

A substantive insight gleaned during this first meeting pertained to the term "Quality of Life". The RSS staff and students wondered if and how this academic and abstract term could be better conceptualised for use with AN students. They explained how AN people often greet each other by asking: "Are you good?" In response, we chose to focus on the research question "What makes life good?", while also maintaining QOL as the theoretical theme. In this way, students would work with a culturally congruent concept (having a good life), while also gaining understanding of the more abstract, though ubiquitous, term (QOL).

During this and subsequent meetings, we determined that students would be open to participating in focus groups. To ensure students' comfort and representation, we offered 6 focus groups stratified by gender and life circumstance: 1 female-only group, 1 male-only group, 3 mixed-gender groups and 1 non-traditional student group (students who were older, working and/or supporting families). We strived to minimise barriers to participation by conducting most study-related activities in the RSS' gathering room (a venue considered safe and convenient), by offering students a \$30 gift card to a local grocery store and providing refreshments and meals.

After conducting the focus groups, students participated in co-analysis workgroup sessions to synthesise the 35 themes identified across the 6 focus groups into mutually exclusive domains (31). In collaboration, students and researchers were able to whittle down the number of domains to 8, while maintaining the integrity of each domain and their meaning to AN college student QOL.

### *Disseminate findings and knowledge gained to all partners*

After developing the QOL measure, the collaborative hosted an interactive findings forum during which focus group participants, RSS staff and researchers discussed findings and reviewed the draft QOL survey. During the forum, students shared their feedback and suggestions for improvement. For example, one recommendation was to move the demographic questions from the end of the survey to the beginning. As students explained, they were accustomed to starting their interactions with others by introducing themselves vis-à-vis their family and community of origin. One student expressed: "You're asking me all of these personal questions without getting to know me first".

### *Integrate knowledge and action for mutual benefit of all partners*

RSS and CANHR reside within the same university. Nevertheless, a mutually beneficial relationship had not been established and thus trust needed to be fostered. As with more "traditional" community-academic collaborations, forging trust and commitment involved both formal and informal meetings, and a policy of open and constant communication. In our case, in-person meetings (at RSS) were preferred, as email and phone-calls could easily be misinterpreted. The frequent visits to the RSS department for meetings and impromptu check-ins provided researchers opportunities to develop rapport with RSS staff and students, and served to demonstrate an example of respectful collaboration. In addition, partners participated in cultural events and presented at research symposia offered both on- and off-campus (33). These chance and planned encounters helped demonstrate and confirm partners' shared commitment to serving the AN community. Furthermore, efforts of RSS staff to promote the project publicly demonstrated earnest commitment to the research collaborative.

Regardless of RSS' sponsorship of the study, soliciting AN students' participation also entailed nurturing trust. As expected, confidence-building efforts required time, energy, patience, and a guiding framework that ensured a culturally respectful orientation and approach to the research process. As partners, students, RSS staff and CANHR researchers successfully undertook the dual roles and responsibilities as learners and experts in all aspects of the research process (7,8,34). Nevertheless, the collaborative process to develop a QOL measure was only a beginning step to establishing research trust among AN students. The frailty of this trust was confirmed during the findings sharing forum when students cautioned that data collection using our newly developed QOL survey would meet scrutiny among AN students; particularly those who were not part of the CBPR development process. As we continued with Phase II of

the project (QOL measure implementation with at least 100 AN students), we were vigilant about building upon (as opposed to relying on) the foundation of trust we had only begun to construct.

## Conclusions

College students are often considered to be accessible and willing participants in academic research pursuits (24). This is often not the case for AN students given a long-standing legacy of mistrust towards research among AN people. In appreciating the personal and historical experiences of the AN student community, particularly with regard to research, it was especially important to adhere to a collaborative, participatory and co-learning research approach. The activities comprising Phase I of this 2-phase project were vital to building trust and providing a safe and positive opportunity for AN students to engage in an academic research endeavour. In addition to achieving our research aim to develop a culturally grounded QOL measure, we also facilitated an empowering experience for AN students who became co-investigators in a process that might normally be regarded with mistrust and suspicion.

As we move forward with our programme of research, we are acutely aware of the fragile nature of collaboration and the work required to achieve the benefits of an equitable partnership. The intent of exploring our CBPR process was to reflexively elucidate challenges and facilitators to engaged research with AN students for whom a vigilant respect for cultural values and historical experiences was paramount (34–37). Equally, if not more important than developing the QOL measure was initiating the foundation for a new legacy of trust and ethical research with AN people.

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