What is ACCORDS?

Adult and Child Center for Outcomes Research and Delivery Science

ACCORDS is a ‘one-stop shop’ for pragmatic research:

- A multi-disciplinary, collaborative research environment to catalyze innovative and impactful research
- Strong methodological cores and programs, led by national experts
- Consultations & team-building for grant proposals
- Mentorship, training & support for junior faculty
- Extensive educational offerings, both locally and nationally

ACCORDS Upcoming Events – mark your calendars!

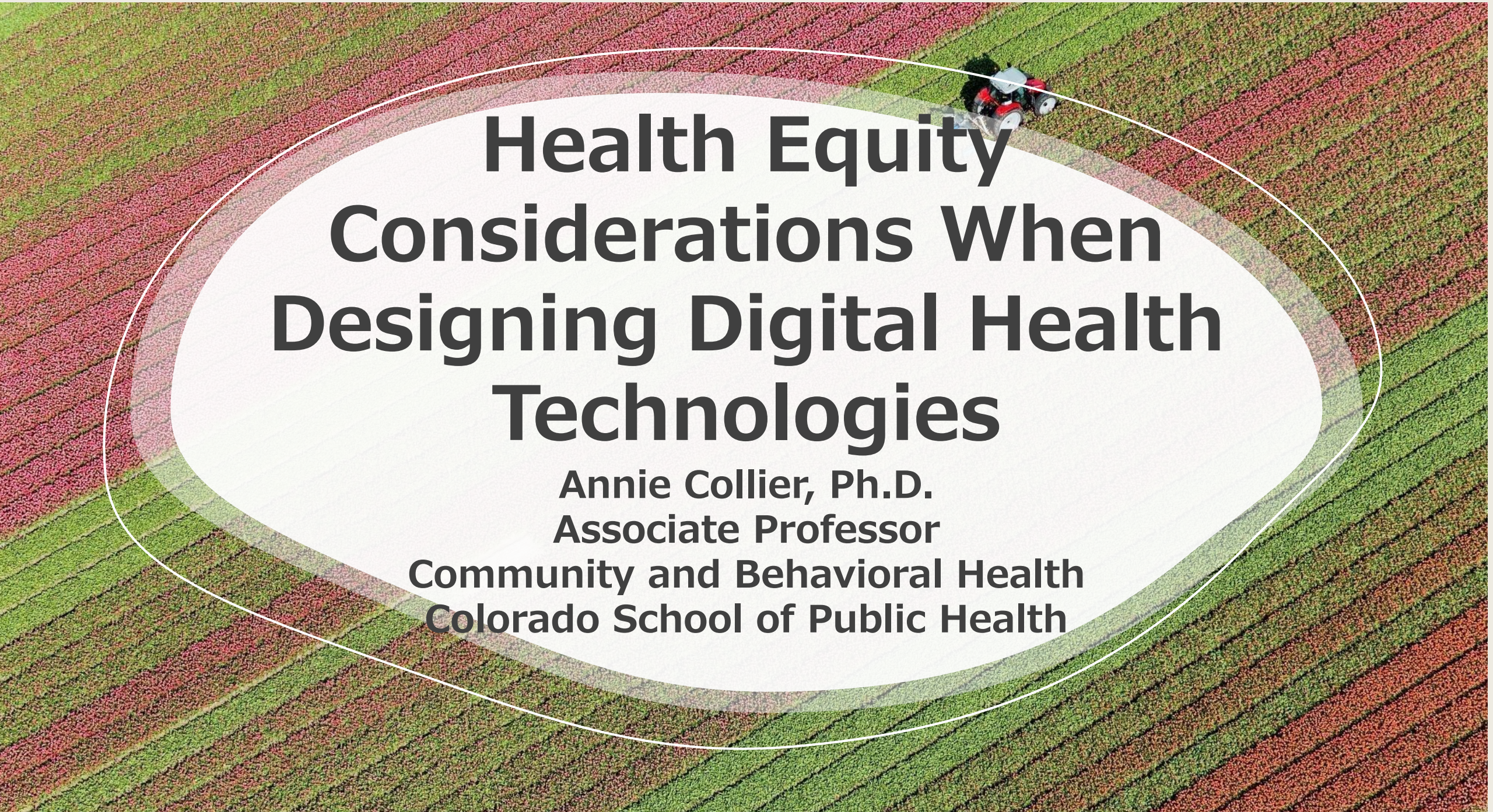
January 13, 2025 AHSB 2200/2201	**Digital Health and Applied Clinical Informatics** Ethics in Bias in Artificial Intelligence *Presented by Matt DeCamp, MD, PhD*
January 15, 2025 Virtual	**Transforming and Advancing a Learning Health System: Multiple Perspectives for Mutual Gain** Ken Kawamoto, MD, PhD
February 2025 Day 1 (2/14): AHSB Day 2 (2/28): Zoom	***New Workshop*** ACCORDS/CCTSI Pragmatic Research Planning Workshop *Registration live on ACCORDS Education website!* Rolling application cycle; due latest by January 10, 2025
Annual Conference June 4-6, 2025 9:00-3:30pm MT	**Colorado Pragmatic Research in Health Conference** Future of Pragmatic Research: Building Multidisciplinary Teams for Innovation and Impact

Emerging Topics in Digital Health & Clinical Informatics

2024-2025 Seminar Series

Presented by:
Annie Collier, PhD, MS

Health Equity Considerations When Designing Digital Health Technologies



Health Equity Considerations When Designing Digital Health Technologies

Annie Collier, Ph.D.
Associate Professor
Community and Behavioral Health
Colorado School of Public Health

Agenda

- What do we mean by digital health and health equity?
- Community engagement and co-design
- Important Considerations
- Case examples and cautionary tales
- Summary and questions

DIGITAL HEALTH TECHNOLOGIES

Digital health “includes categories such as mobile health (mHealth), health information technology (IT), wearable devices, telehealth and telemedicine, and personalized medicine.”

-- FDA definition

Health Equity

Everyone should have a fair and just chance to achieve the best health possible, regardless of their race, ethnicity, disability, sexual orientation, gender identity, socioeconomic status, geography, or other factors

TERMINOLOGY TO CONSIDER

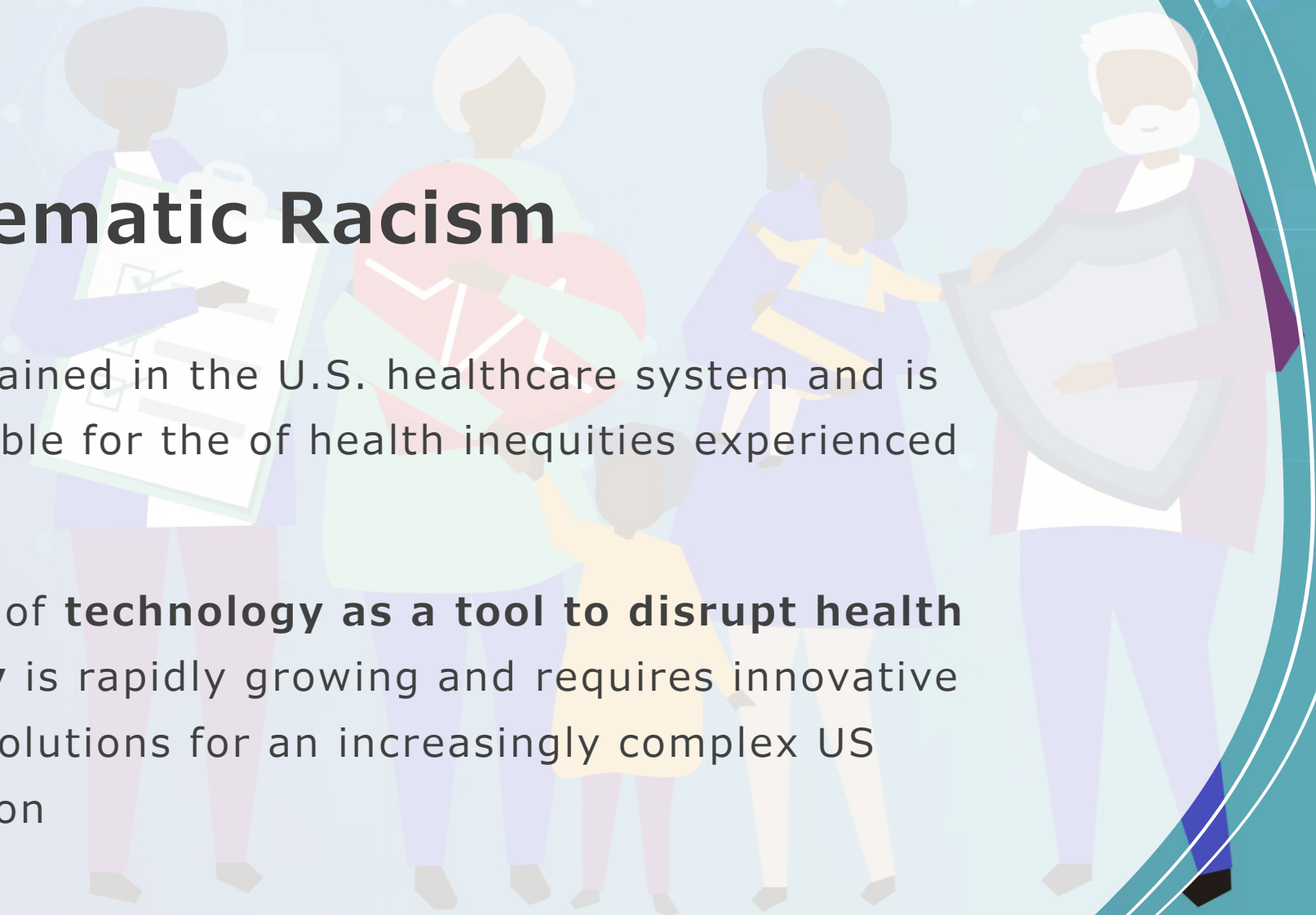
- **<u>Minority Health:</u>** Distinctive health characteristics and attributes of racial and/or ethnic minority populations who are socially disadvantaged due in part to being subjected to racist or discriminatory acts and are underserved in health care. *USA OMB definition includes AI/AN, Asian, Black or African American, Hispanic or Latino American, Middle Eastern or North African, Native Hawaiian or Pacific Islander*
- **<u>Health Disparities</u>**: central core concept identifies how race, ethnicity, and socioeconomic status interacts with health determinants, such as social determinants, individual behaviors, the physical and cultural environment, and biological systems, to lead to differential clinical and population health outcomes. *Populations that experience health disparities include racial and ethnic minority groups, people with lower SES, living in underserved rural communities, sexual and gender minority groups, people with disabilities.*
- **<u>Terminology to Avoid:</u>** Vulnerable, marginalized, and high-risk – stigmatizing language and vague. Try to use person-first and destigmatizing language. Important not to suggest these characteristics are inherent to a group or imply affiliation references actual causal factors

https://www.nimhd.nih.gov/resources/understanding-health-disparities/minority-health-and-health-disparities-definitions.html#:~:text=Health%20Disparity%20Definition,or%20eliminate%20adverse%20health%20outcomes.

Systematic Racism

…is ingrained in the U.S. healthcare system and is responsible for the of health inequities experienced

The use of **technology as a tool to disrupt health inequity** is rapidly growing and requires innovative design solutions for an increasingly complex US population



Outcomes Associated with Health Disparities

- **Higher incidence and/or prevalence of disease**, including earlier onset or more aggressive progression of disease.
- **Premature or excessive mortality** from specific health conditions.
- **Greater global burden of disease**, such as Disability Adjusted Life Years (DALY), as measured by population health metrics.
- **Poorer health behaviors and clinical outcomes** related to the aforementioned.
- **Worse outcomes on validated self-reported measures** that reflect daily functioning or symptoms from specific conditions.

UNFORTUNATELY, THERE IS DIGITAL DIVIDE WITH COMPLEX DETERMINANTS

Policy and structural determinants: e.g., more likely to have internet and fiber broadband in high income areas (digital redlining); not accessible to all

System-level determinants: Lack of investment in services and digital infrastructure for POC, e.g., entrepreneurs of color receive 1-2% of funding or start ups. Over-representation of White and Asian founders. Prioritize health equity and innovation.

Community/social level determinants: e.g., do communities know about potential benefits of technology and health? Are they even brought to the table and supported in considering these as solutions?

Individual level determinants: What skills are needed in order to use the digital tools and platforms? What is the motivation?

Digital health intervention level determinants: Tools need to be straightforward and usable. Language and literacy, accessibility. Are designers educated about the complexity of engaging diverse communities?

(see Lyles et al., 2023)

Benefits of Mobile Health Applications (mHealth)

Facilitates earlier and more effective physical and mental health interventions

Offers unique opportunities for monitoring progress, providing education materials, receiving personalized prompts and support, collecting ecologically valid data, and using self-management interventions when and where they are needed

Helps providers reach people who do not have ready access to healthcare services, especially in remote areas where healthcare is absent or lacking

See Chi et al., 2016

My Background in Digital Technology

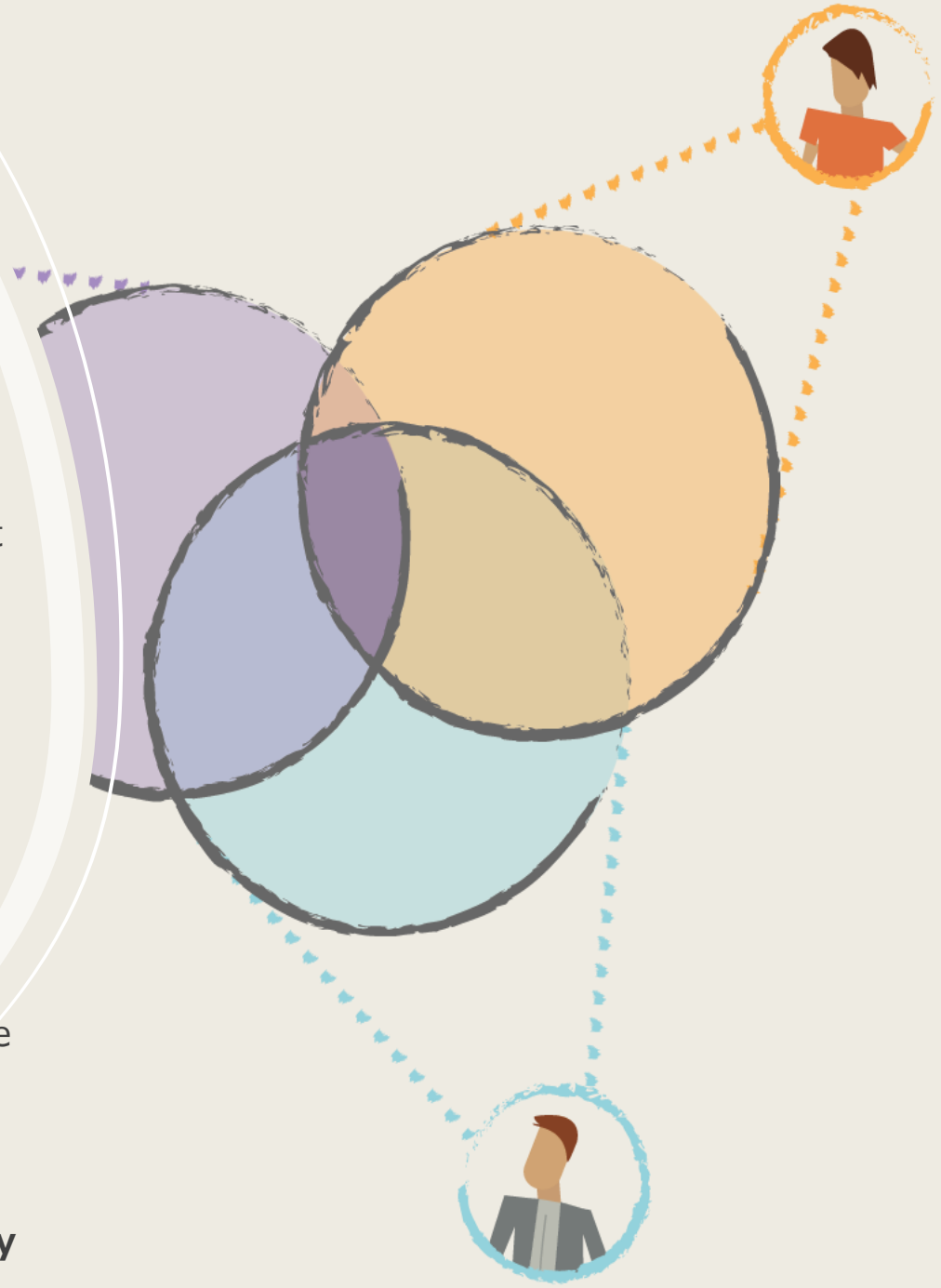
- Building new and modifying existing mental health and substance abuse apps
- Integrating AI/chatbots into substance use education
- Evaluating the acceptability and feasibility of using algorithms in primary care settings within a tribal health organization
- Using virtual reality interventions for stress management and well-being
- Ongoing community engagement for technology program development, planning, interventions, and evaluation, including for above

CO-DESIGN AND COMMUNITY ENGAGEMENT ARE CRITICAL

- Participatory research methods involve intended users at every stage, including determining feasibility and acceptability, research design, implementation, evaluation, refining and updating as it matures
- Need to understand the motivations and challenges that users face, including special circumstances or requirements of your target group
- Incorporates values, language, knowledge

Why Co-Design is Essential

- Underserved communities typically have experienced marginalization; they will not automatically trust you or what you are offering. *Takes time to establish trust* and find out what they need and want.
- Many marginalized groups have experienced *unethical research practices* in the past. How will you be different?
- Do you know what the community's *strengths and resources* are? Are you even asking about these? Needs to be considered and incorporated into what you are designing
- Is your intention to "leave" the product with the community (it should be!)? Then *build capacity*, empower them, and involve them in co-learning so they can



It is imperative for dissemination to have strong community engagement

CONSIDER MORE CREATIVE APPROACHES TO HOW YOU INTERACT WITH COMMUNITIES INSTEAD OF “TALKING” MEETINGS

Our tendency as researchers is to walk in and begin asking questions

Always start with icebreakers and share personal information. Take your researcher hat off and be a person first. Provide people with additional context about who you are, including your non-Academic roles and if you are comfortable, your identities.

Instead of “talking”, consider use of the following:

- Use of photovoice
- Zines
- Collage to determine understanding, values, goals
- Card sorting to establish priorities
- Rank order theoretical and cultural strategies
- Provide interaction time with prototypes
- Use creative approaches, such as drawing/artwork for feedback

CO-DESIGN OFTEN INVOLVES TAKING TIME TO BUILD RELATIONSHIPS

Many NSF and NIH grants allow for planning grants, e.g., NSF Smart and Connected Communities (S&CC)

CHALLENGES TO THINK ABOUT

Again, involve the target population

- To ensure the app is relevant and of interest to the intended population, include experts and potential users from the target population in the design process. They can help you understand the unique roles of language, age, gender, religion, culture, etc.

Think about health literacy and digital literacy

- Low health literacy can be a barrier to mHealth use, especially for low-income populations. Simple language is important (simple, clear).

- People often do not have the same level of digital literacy as you expect across multiple contexts, given that they use smartphone. Consider what is relevant to these communities and ask!

Technological accessibility

- Not everyone has access to smartphones or live internet, and the cost can be a barrier. Widely disparate infrastructures, within the USA, across states, on reservations. Buying the technology for the community is not always a good solution.

ADDITIONAL CHALLENGES

Physical abilities

Is technology built only for able-bodied people? What about people who need accommodations, such as vision?

Security and privacy

Security breaches can violate patient privacy, so it's important to ensure that technology is secure and protects patient health data. There will be mistrust about sharing information. At the same time, too complex of security measures will backfire.

User retention and stickiness

It can be challenging to get users to keep returning to technology, even if it's convenient.

Break away from “individualist” Western concepts

Think about interdependence and sub-communities, including families, hamlets, villages. What is the role of the parent, caregiver or extended family/community in the technology? Should you give them a role? Can you accommodate multiple perspectives in what will be included?

Outdated technology

All tutorials and informational materials need to be updated regularly

Cultural Considerations

Incorporate ecological knowledge and social values. However, what if these are not well articulated or agreed upon? Try not to make assumptions.

Be aware of special holidays, special customs and traditions. These will impact every stage of the research.

Postcolonial (theoretical orientation that acknowledges the impacts/harms of colonization) and **decolonia**l (think through what it means to build systems informed by power differentials and Western-centric values) computing

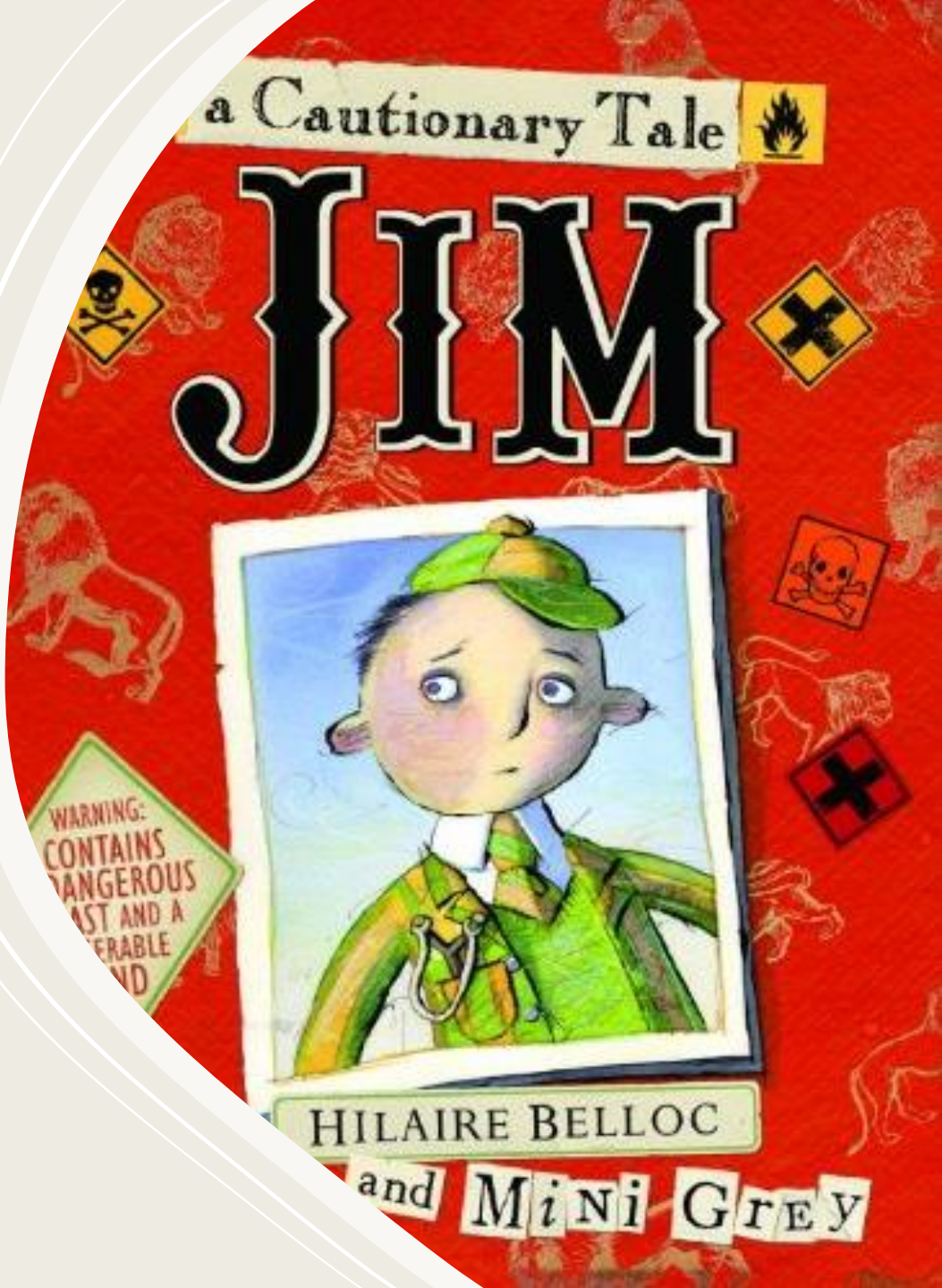
Data sovereignty –maintain, control, protect and develop cultural heritage, traditional knowledge and traditional cultural expressions, as well as right to maintain, control, protect and develop their intellectual property over these. *What if no infrastructure for this? No IT, no IRB, no technical expertise*

Additional Cultural Considerations

- Transferability and generalizability – small sample sizes and unique issues for each group
- Digital Equity – many places are remote and have no access to highspeed internet, or it is intermittent (asynchronous information exchanges); many have no devices; many have poor digital literacy
- Language – challenging to translate Western concepts into languages, including emotions. Need for greater visual and auditory content, not just text. Awareness that many cultures have rich oral traditions.
- Tension within generations – different approaches in youth and adults within same culture
- Historical Trauma

Cautionary Tales

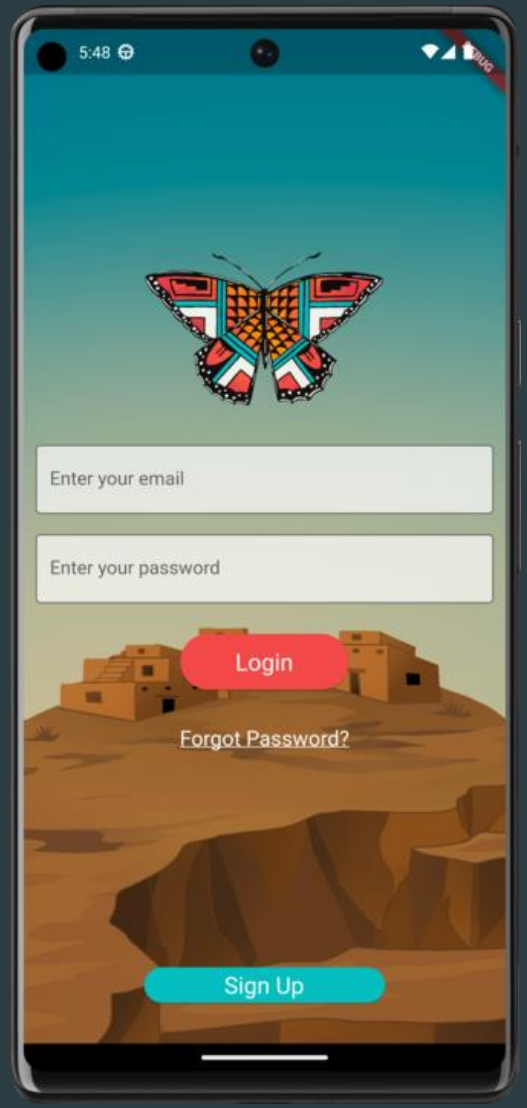
- Ground-up vs. top-down considerations
- Term “cultural adaptation” carries negative connotations
- Evidence-based treatments in the dominant culture may have little relevance or meaning in other cultures; often not even tested in different cultural groups
- Strengths and asset-based approaches are critical



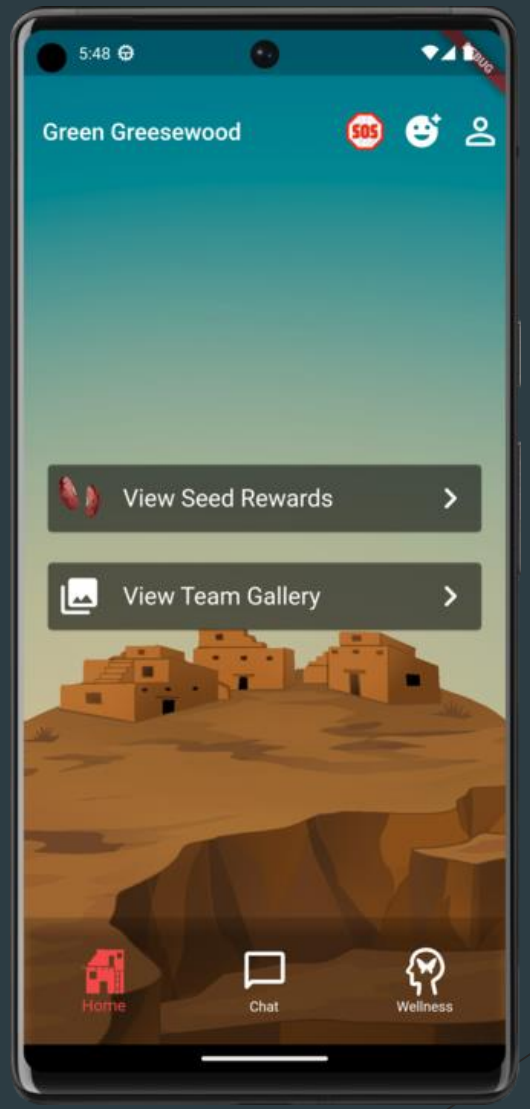
Examples from Qöyangnuptu Hopi App

- Came to the table with evidence-based strategies, especially those that had been used with AI/AN people before (e.g., trauma informed approaches, narrative approaches, mindfulness practices). *Poorly understood, not relevant or personally meaningful*
- Cultural preferences and needs related to mental health; *historical experience with behavioral health services biased people's willingness to engage; preference for Hopi cultural ways*
- Attempted to culturally ground theory behind each activity. *Difficult to get people to agree on what that meant. Different beliefs about religion and traditional cultural practices. Within the culture, negativity about other tribal communities*
- Artwork and imagery for visuals - *agreed*
- Hopi language – high priority to teach young people the language and cultural ways – *agreed, but differences in use of language, how to describe concepts*
- Wanted activities that involved cooperation and support*; this was different for youth and adults*
- Peer mentor program – kids talking to other youth and not adults. *Difficult to get mentors to participate.*

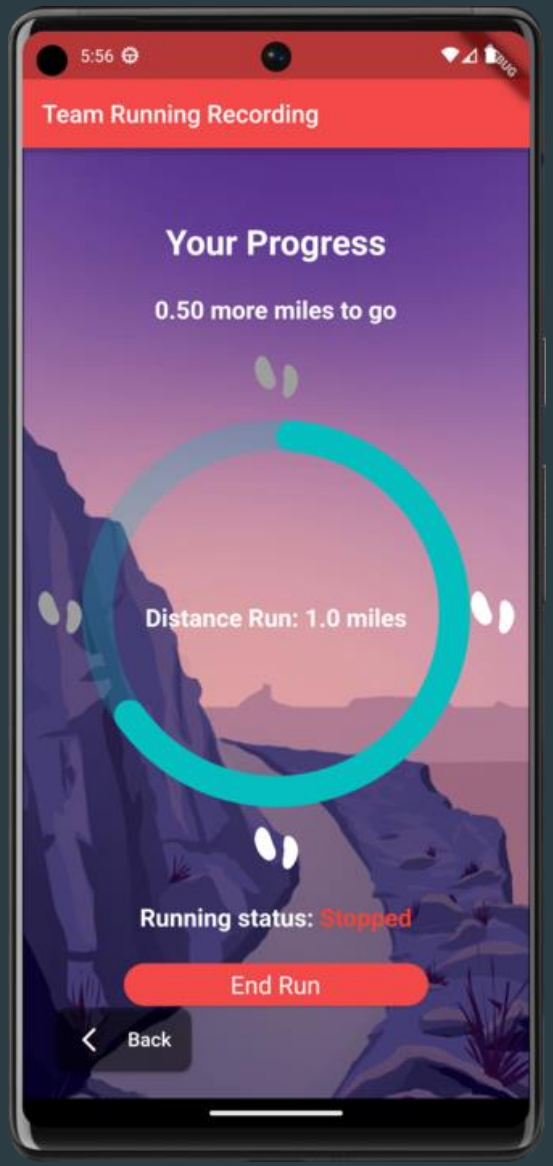
- Login screen



- Home page

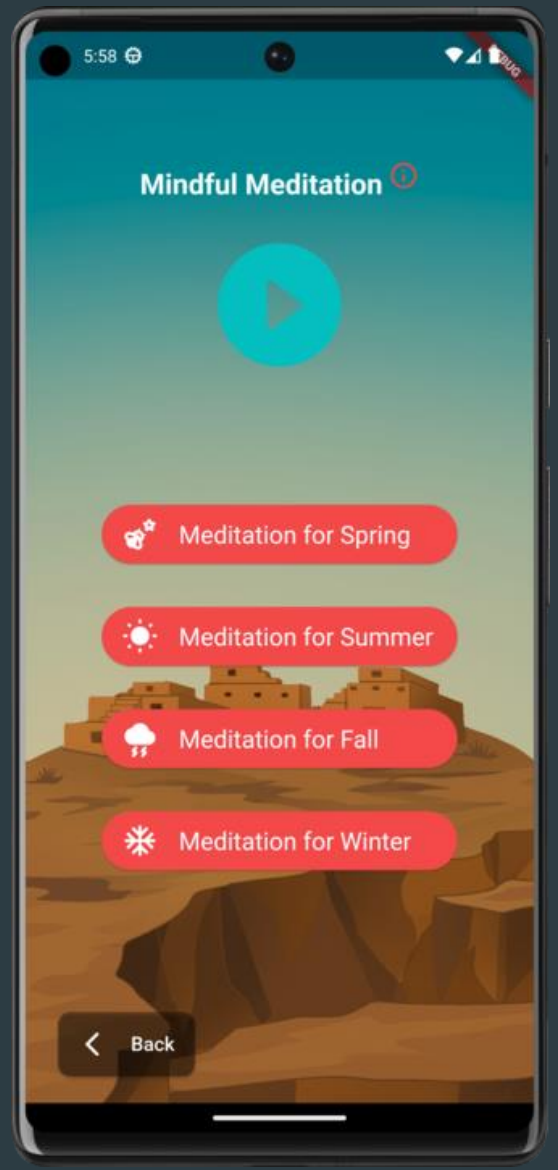


Team Running

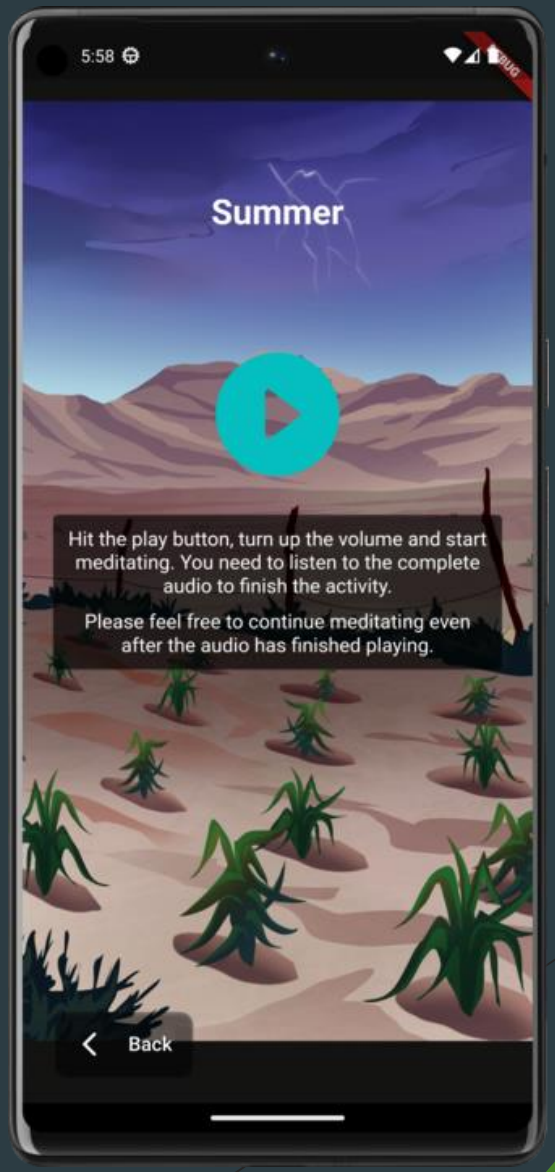


Mindful Meditation (4 Options)

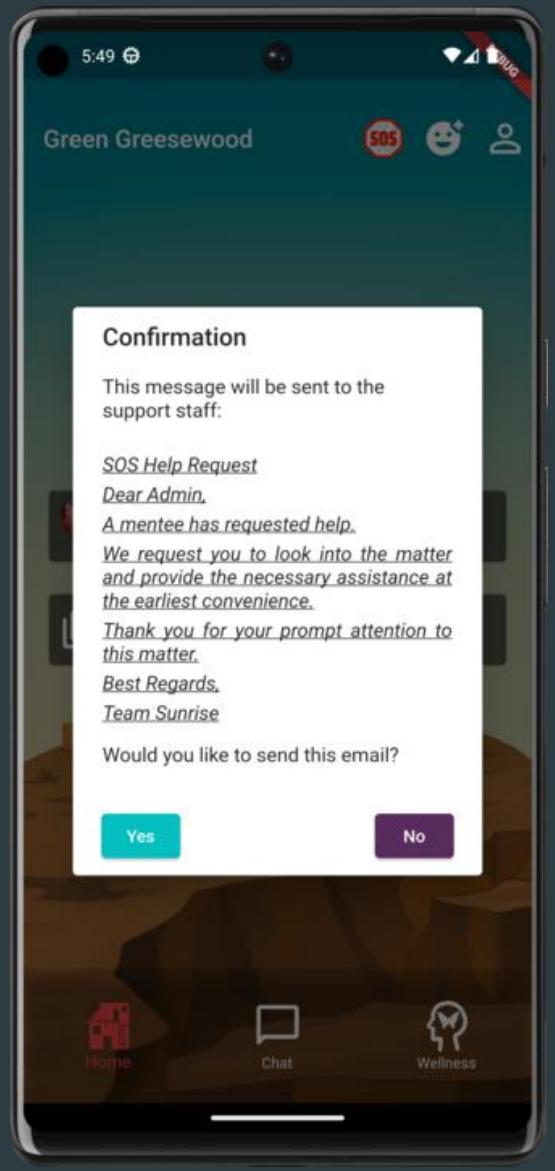
- Home Page

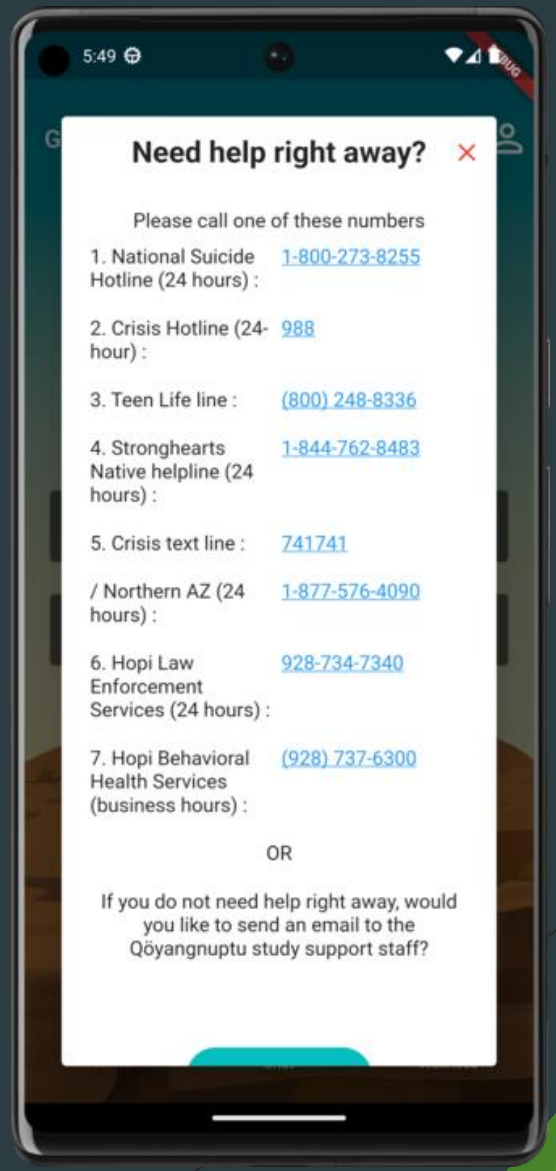


- Summer Meditation (Example)



SOS Button

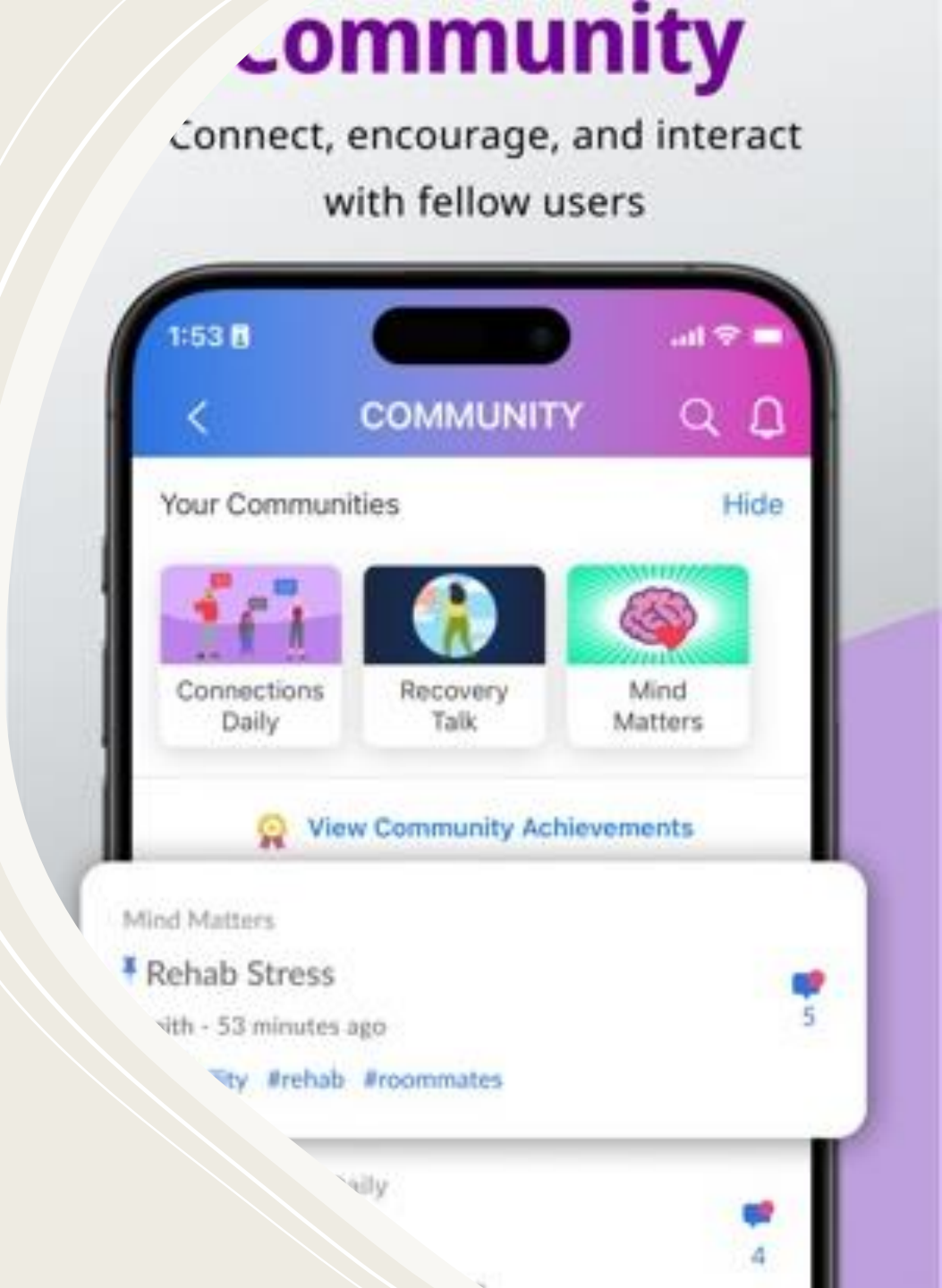

5:49
Green Greesewood
SOS
Confirmation
This message will be sent to the support staff:
SOS Help Request
Dear Admin,
A mentee has requested help.
We request you to look into the matter and provide the necessary assistance at the earliest convenience.
Thank you for your prompt attention to this matter.
Best Regards,
Team Sunrise
Would you like to send this email?
Yes
No
Home
Chat
Wellness


5:49
Need help right away?
Please call one of these numbers
1. National Suicide Hotline (24 hours) : 1-800-273-8255
2. Crisis Hotline (24-hour) : 988
3. Teen Life line : (800) 248-8336
4. Stronghearts Native helpline (24 hours) : 1-844-762-8483
5. Crisis text line : 741741
/ Northern AZ (24 hours) : 1-877-576-4090
6. Hopi Law Enforcement Services (24 hours) : 928-734-7340
7. Hopi Behavioral Health Services (business hours) : (928) 737-6300
OR
If you do not need help right away, would you like to send an email to the Qöyangnuptu study support staff?

CIRCLE:

MODIFICATION OF CHESSHEALTH APP FOR ALASKA NATIVE PEOPLE EXPLORING SOBRIETY

- *CONNECTIONS* is an “Evidence-based smartphone app that reinforces coping and recovery skills to help individuals adhere to their treatment plan and stay in recovery”
- App widely used by departments of health and behavioral health, human services, tribal health programs, drug courts, universities and public-school systems
- Smartphone app with 24/7 moderated peer support services, discussion groups, video support groups, interactions available with providers, built in contingency management and assessment, content for learning, gamification and badges
- SCF Research Team reviewed multiple “off the shelf” apps and tried one before abandoning that approach and using CHESS app



Adaption of CONNECTIONS for Southcentral Foundation (SCF) Customer-Owners

Southcentral Foundation

- Curated, modified and added special content (e.g., recipes, blogs, podcasts) for Alaska Native people
- Wanted to integrate the “Community Reinforcement Approach” (psychosocial approach) for substance use. This involved transtheoretical model; supporting; recreational and vocational self-management skills; also involved contingency management, goal setting, coping, etc.
- SCF wanted a closed-system to interact only with SCF customer owners and staff
- Visually could not change the look and feel of the app, or many features

Challenges with CHESS/CONNECTIONS App

- Smartphones are not equal; 2/3's of user smartphones were older and they could not access the app
- CONNECTIONS was highly grounded in Western viewpoints and not Indigenous beliefs
- Updates over-wrote our modifications; put us many months behind
- Wanted additional features (like journaling); these could not be easily added and then when they were, not promoted since not part of the app
- Could not turn off or modify many of their features, like daily check ins, "thoughts of the day" SOS system, location settings (for high risk to drink), assignment to teams
- Could not easily offer users information security, e.g., their system insisted on valid email to sign up, emergency contact information
- Poorly set up for individuation, including for disability, gender identity
- By modifying their app to meet requirements of the tribal health organization we lost many features that were highly evolved in CONNECTIONS

Questions and Comments

Thank You

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Suggested Resources

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Lyles, C. R., Nguyen, O. K., Khoong, E. C., Aguilera, A., & Sarkar, U. (2023). Multilevel determinants of digital health equity: a literature synthesis to advance the field. *Annual review of Public Health, 44(1),* 383-405.

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Vigil-Hayes, M., Collier, A. F., Hagemann, S., Castillo, G., Mikkelson, K., Dingman, J., ... & McLaughlin, A. (2021). Integrating cultural relevance into a behavioral mHealth intervention for Native American youth. Proceedings of the ACM on human-computer interaction, 5(*CSCW1*), 1-29.

Jackson, D. N., Sehgal, N., & Baur, C. (2022). Benefits of mHealth co-design for African American and Hispanic adults: multi-method participatory research for a health information app. *JMIR Formative Research, 6(3*), e26764.

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