

Cultural Adaptation of a Suicide Prevention Intervention for Native Communities

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Caring Texts: A Strength-Based Suicide Prevention Trial in 5 Native Communities

(R01MH106419; PIs: Nelson & Comtois)



Partnerships *for* Native Health



Session Overview



- Intervention Overview
- Study Background
- RCT Study Design
- Phase 1 Cultural Adaptation Goals and Process
- Qualitative Methods
- Findings and Resulting Adaptations
 - Eligibility Criteria
 - Participant Experience
 - Cultural Content/ Messages
 - Outcome Measures
- Effects of Adaptations on Study

What is the Caring Contacts Intervention?



- Caring messages sent to people with suicide risk over the course of a year
- Provides care and support, asks for nothing in return
- “Magic ingredient” is social connection
- Letters, Phone, Emails , Texts



Dear _____,

It has been some time since you were here at the hospital, and we hope things are going well for you. If you wish to drop us a note we would be glad to hear from you.

Sincerely,



Death



Attempts



Thoughts

Sample Text Messages



- David – Good to meet you yesterday. Check out our website: www.care.org. Hope the resources are helpful. – Kate
- Hey David – It's Kate from the Care Study. Hope you've had a good week. www.care.org
- Hi there David - Hope life is going well. – Kate www.care.org
- Happy Birthday, David! Hope you have a wonderful day and a positive year ahead. – Kate www.care.org

Introduction and Background

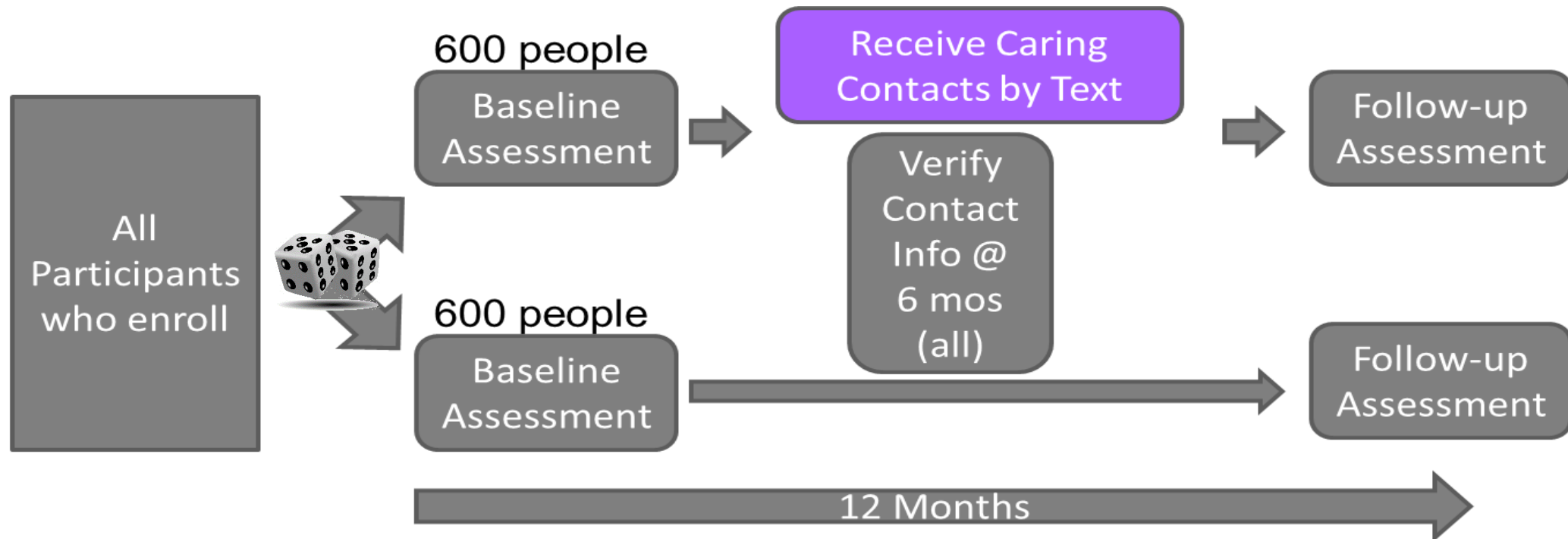


- In the context of rising suicide rates, and the high levels of death by suicide in Indian Country, we need a sustainable, evidence-based prevention approach.
- Caring Texts: A Strengths Based Suicide Prevention Trial in 5 Native Communities
 - Phase I: Cultural Adaptation and Tailoring
 - South Central Foundation, Fort Peck, Pine Ridge, Cheyenne River, Cherokee Nation of Oklahoma
 - Phase II: Randomized Clinical Trial
 - N= 1200 (planned); 711 (actual) across all 5 sites

RCT Study Design



- Each participant is randomly assigned for 1 year to:
 1. Usual care alone OR
 2. Usual care + Caring Texts



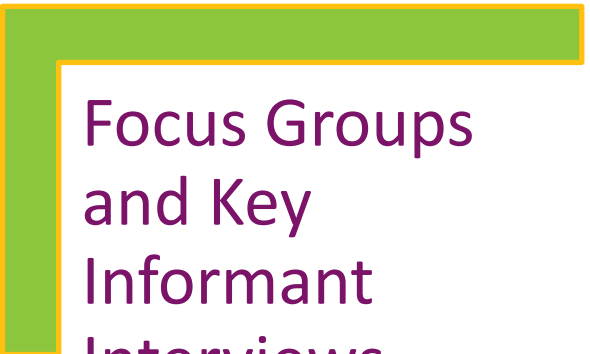
Phase I Goals



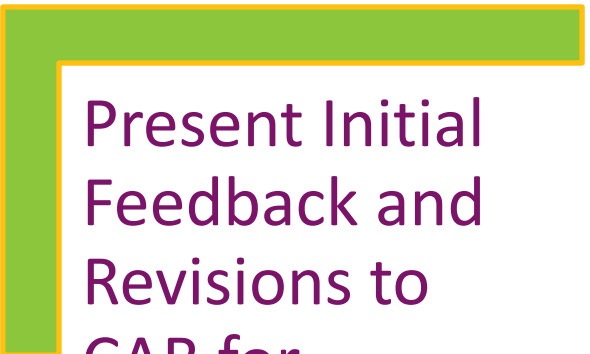
- Gather community input on study design
 - Make changes based on community feedback
- Tailor the messages to the communities
- Make sure assessment items are clearly worded
- Make sure study materials are clearly worded
- Make this study acceptable and appropriate for AI/AN communities
- Increase likelihood of success



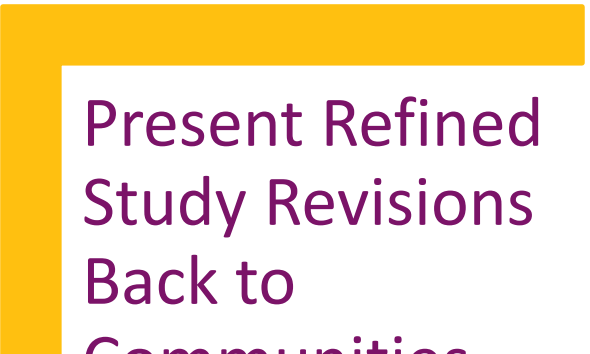
Phase I Process



Focus Groups
and Key
Informant
Interviews

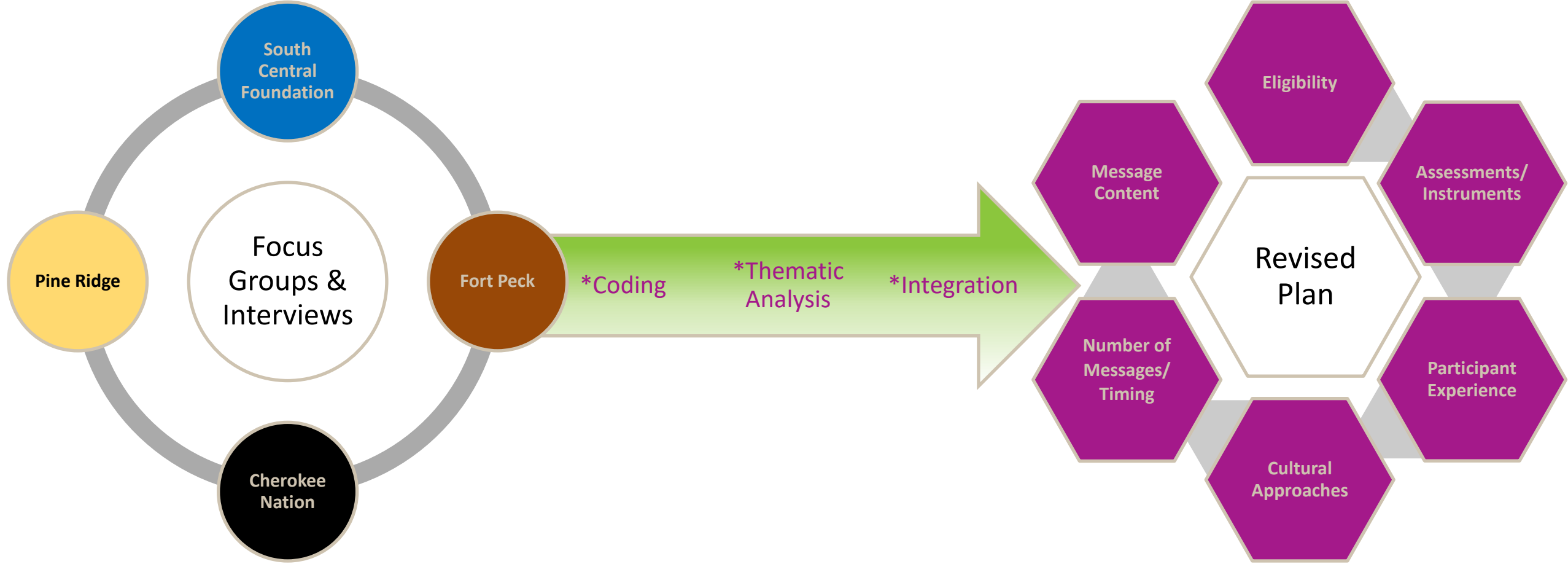


Present Initial
Feedback and
Revisions to
CAB for
Refinement



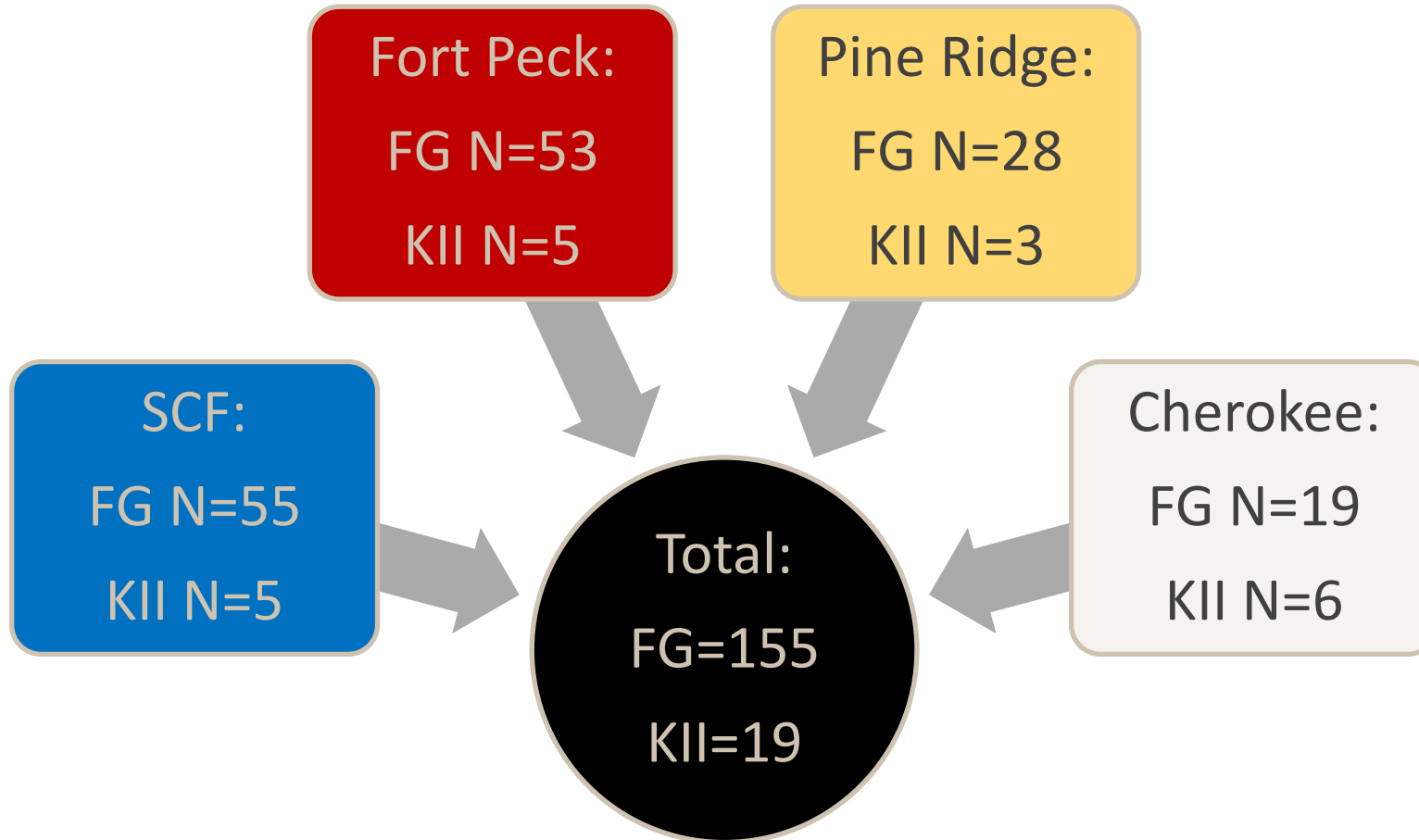
Present Refined
Study Revisions
Back to
Communities
for Finalization

Initial Process



***Special Shout Out to the SCF team: Jen Shaw, Kelly Jansen, and Jaedon Avey for all the coding and analysis work!**

Who We Talked To



Coding of Transcripts



- Total codes: 42
 - 11 General Codes
 - 0-6 Sub-Codes each
- Total excerpts coded = 1015
 - Message Timing and Number
 - Message Content
 - Eligibility Criteria
 - Participant Experience
 - Cultural Issues and Adaptations
 - Assessment and Interview Items

The screenshot displays the dedoose web application interface. The top navigation bar includes 'Home', 'Codes', 'Media', 'Excerpts', 'Descriptors', 'Analysis', 'Memos', 'Training', 'Security', 'Data Set', and 'Projects'. The main content area is divided into several panels:

- Project: Phase 1 Focus Groups:** A summary panel showing counts for Users (5), Media (35), Descriptors (24), Excerpts (1015), Codes (43), and Code Applications (1645). It includes 'Import Data' and 'Export Data' buttons.
- Media:** A table listing media files with columns for Type, Title, Added, User, # Ex, and Length. The table contains 12 rows of data.
- Codes:** A tree view showing a hierarchy of codes. The 'Follow-up phase' is expanded, showing sub-categories like 'Instrument/Interview Items', 'Sample', 'Caring Text Messages', 'Message Timing', 'Message Form', 'Message Content', 'Message Tone', 'Other Message Suggestions', 'Characteristics', 'Age', 'Gender', 'Rural/Urban', and 'Community'. Under 'Community', 'Response to Suicide Risk' and 'Methods of Suicide' are visible.
- Excerpts: 1015:** A list of excerpts with columns for Resource, Added, Username, and Codes. It shows several excerpts with their respective resource names and dates.
- Codes x Descriptor:** A panel showing a bar chart for 'Follow-up phase' and 'Instrument/Interview Items'. The 'Follow-up phase' chart shows 100% for CN, 12.2% for Fl Peck, 16.4% for Pine Ridge, and 0.8% for SCF. The 'Instrument/Interview Items' chart shows 88.1% for CN, 3.8% for Fl Peck, 0.9% for Pine Ridge, and 0.2% for SCF.
- Descriptor Ratios:** A panel showing four pie charts for 'Site', 'Type of Event', 'Primary respondent type', and 'Secondary Respondent Type'. The 'Site' chart shows 100% for CN, 100% for Fl Peck, and 100% for Pine Ridge. The 'Type of Event' chart shows 100% for PG. The 'Primary respondent type' chart shows 100% for Tribal. The 'Secondary Respondent Type' chart shows 100% for Tribal.

Eligibility Criteria Themes



“We have a lot of Elders who are dying by suicide”



Suggestions

- Remove age limits
- At least the upper limit so you include veterans
- Including rural communities (phone?)
- Don't make phone a criterion, use facebook messenger

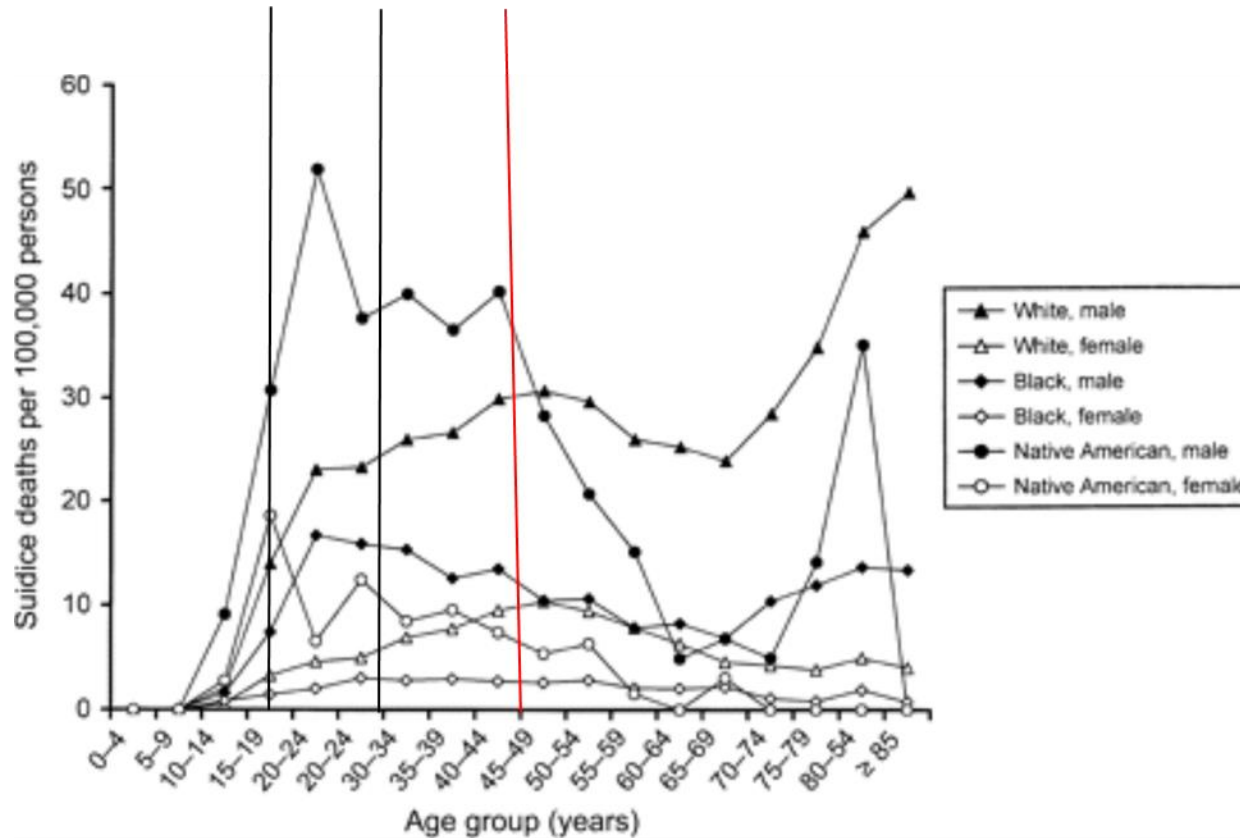
Cautions

- Most understood difficulty of including <18 years
- Others mentioned despite poverty, everyone had a phone

Eligibility Discussion Points



- Age:



From: Suicide and Suicidal Behavior

Epidemiol Rev. 2008;30(1):133-154. doi:10.1093/epirev/mxn002

Epidemiol Rev | Epidemiologic Reviews Published by the Johns Hopkins Bloomberg School of Public Health 2008.

Eligibility Changes



- Age: There will no longer be an upper age limit.
- At what age does texting not happen any more?
- Having a phone will no longer be a requirement
- We will be including mail, email, postcards to reach people

Part. Exp. Content Themes



“You’re hearing things that not everyone gets to hear.
You need to honor and respect that.”



Suggestions

- Preference for in-person screening and baseline interviews
- Develop rapport before administering any study instruments
- Order questions from least to most sensitive
- Conduct baseline in a comfortable, private environment

Cautions

- The no treatment control group doesn’t feel right
- Standardization of instruments and messages feels disrespectful
- Be sure reading level isn’t too high on study materials (suggested 5th grade level)

Partic. Experience Changes



- There will be a *strong preference* for in-person screening and baseline
- Second preference will be videoconferencing
- If videoconference not possible, phone will be used if participant wishes
- There will be different “tracks” of messages appropriate to the person’s relationship to the interviewer.
- The control group isn’t “no-treatment”

Cultural Content Themes



“Knowing cultural values- humility, leadership, help others- these things bring purpose and meaning to life.”



Suggestions

- Enculturation as healing
- Content should refer to local stories and metaphors
- Being connected to culture is a sign of wellness
- Traditional practices as a “re-birth of culture”

Cautions

- Not everyone is very enculturated across sites
- Diversity of traditionalism
- Hence, the need for “tracks” of messaging
- Very site specific

Culture Discussion Points



- Stomp dance, green corn, solstice, Cherokee national holiday - (CN)
- Sundance, medicine man, powwows, singing, moons and seasons - (SD)
- Fishing, berry picking, hunting; AFN can be a rough time but also a time for re-connecting with one's culture. Native dance, language programs – (SCF)
- Equine therapy, Archery, Sweats- (FP)
- Site coordinators drafted individual message banks in collaboration with PIs to ensure appropriateness

Existing Text Messages



Text	Delivery day	Example Text*
1	One day after enrollment	John – Good to meet you yesterday. Check out our website: www.careteam.org . Hope the resources are helpful. – Kate
2	One week after enrollment	Hey John – It's Kate from the CARE team. Hope you've had a good week.
3	One month after enrollment	Hi John, Hope all's well and you're taking good care of yourself. – Kate careteam.org
4	Two months after enrollment	Hi there John, Hope you're having a good day today. – Kate careteam.org
5	Three months after enrollment	Hey John, Hope things are going well and you're having a good week. – Kate careteam.org
6	Four months after enrollment	Hi John, Hope life is treating you well. – Kate careteam.org
7	Six months after enrollment	Hey John – Just wanted to say hello. Hope things are going OK. – Kate careteam.org
8	Eight months after enrollment	John - Hope everything's going well. – Kate careteam.org
9	Ten months after enrollment	Hello again, John! Hope things are good.– Kate careteam.org
10	One year after enrollment	Hi John, Hope you're having a good day today. – Kate careteam.org
11	Participant birthday	Hey John! It's your birthday! Hope you have a great one and the next year brings you good things! – Kate careteam.org

Message Content Themes



Generally, existing text messages were considered acceptable.



Suggestions

- Incorporate local Native language terms
- Have parallel message “tracks”
- Include some degree of spiritual content
- Resend website periodically
- Tie messages to the seasons
- Encourage engagement in local activities

Cautions

- Avoid being too generic
- Don't say “check out our website”
- Don't be too cheerful, but positive
- Keep in mind life can be tough
- Careful of triggers (anniversaries)
- Facebook messenger?

Possible Adapted Messages



- **At one week:**
- **Original:** John – It's Kate from the CARE team. Hope you've had a good week. – Kate careteam.org
- **CN:** Osiyo John! It's Kassandra from last week. Sending good thoughts your way. There's a list of some things happening that you might be interested in at careteam.org

- **At one month:**
- **Original:** Hi John, Hope all's well and you're taking good care of yourself. –Kate careteam.org
- **SCF:** Aang (Aleut: hello) John, AFN is coming up. If you want to go, you can see the schedule of events here careteam.org – Kelley

Possible Adapted Messages



- **At one week:**
- **Original:** John – It's Kate from the CARE team. Hope you've had a good week. – Kate careteam.org
- **FP:** Hau John, It's Albert Foote. Wanted you to know I'm praying for good things for you. There's a list of some things you might find helpful at careteam.org

- **At one month:**
- **Original:** Hi John, Hope all's well and you're taking good care of yourself. –Kate careteam.org
- **PR:** Hey Maske, I just wanted to remind you that you're important and let you know I'm thinking of you! – Sheralda

Message Timing Themes



Definitely felt 11 was not enough,
monthly minimum frequency.



Suggestions

- Extra messages in “suicide season”
- Tie messages to the seasons
- May need to contact controls more than just at 6 months
- Don’t always make it the same day of the month/week

Cautions

- Recognize tough times of the year
 - “Suicide season”
- Don’t overload people, but don’t seem aloof either
- Facebook messenger?

Message Timing Themes



Consider weekly for first 6 weeks, then bi-weekly for 1-2 months, then monthly



Suggestions

- Recognize economic cycles (per cap, EBT, etc.)
- Tie messages to local events
- Consider time of day as well
- Different tracks should have different events referred to (e.g., college students, traditional cultural events)

Cautions

- No additional cautions

Message Timing Changes



- The day after the baseline, then ~weekly for first 6 weeks, then ~bi-weekly for 1-2 months, then monthly (plus birthday)
- Time of day will be variable, but inside work hours
- Will include additional messages in spring months
- Will refer to seasonal changes in messages sent at those times



Outcome Measure Changes



- Based on community feedback, the wording and content of the outcome measures was adapted to more fully capture the experience of those in the communities we were working within.



Changes to SASI Count



Suicide Attempt and Self-Injury Count (SASI Count)

Original Intro to SASI:

“Now we’re going to talk about self-injury or suicide attempts. For this, I want you to think about any time you have intentionally harmed yourself. This can include a number of different things such as cutting or burning yourself, taking an overdose of pills, banging your head, or punching things.”

Revision Based on Phase I Feedback:

“Now we’re going to talk about times you may have tried to kill or hurt yourself. For this, I want you to think about any time you have tried to kill or hurt yourself on purpose. This can happen a lot of different ways, like cutting or burning yourself, taking an overdose of pills, crashing your car on purpose, or punching things.”

Changes to SASI Count



Original SASI Text:

1. Have you ever intentionally harmed yourself?
2. When was the very first time in your life you intentionally harmed yourself?
 - How accurate is this date?
 - What did you do?
 - Did you intend to die?
 - What happened next?
 - Did you receive medical treatment? What kind?
3. When was the most recent time you intentionally harmed yourself?
4. When was the time that you most severely harmed yourself?

Revised Version:

1. Have you ever hurt yourself on purpose?
2. When was the very first time in your life you hurt yourself on purpose?
 - How sure are you about this date?
 - What did you do?
 - What did you think or hope would happen?
 - Were you trying to die?
 - Were you intoxicated at the time?
 - What happened next?
 - Did you receive medical care? What kind?
 - Did you talk to anyone about it? (before or after?)
3. When was the most recent time you hurt yourself on purpose? (if different, same follow-up questions)
4. When was the time that you hurt yourself the worst? (if different, same follow-up questions)

Changes to SASI Count



Original Intro to Methods:

“It is important for us to get a better understanding of different things you may have done to hurt yourself, your intentions when you hurt yourself, and when you received medical treatment for hurting yourself.”

Revision Based on Phase I Feedback:

“We’d like to get a better understanding of different ways you may have hurt yourself, what you wanted to happen when you hurt yourself, and when you got medical care for hurting yourself.”

Changes to SASI Count



Original List:

1. Cut yourself on purpose?
2. Intentionally overdosed on drugs?
3. Burned yourself on purpose?
4. Attempted to strangle or hang yourself?
5. Jumped from a high place to cause self-injury?
6. Shot yourself with a gun?
7. Swallowed poisons/caustic sub. on purpose?
8. Asphyxiated or smothered yourself?
9. Tried to drown yourself?
10. Stabbed/punctured yourself on purpose?
11. Banged your head, hit yourself, hitting things?

Revised List

1. Cut yourself on purpose?
2. Overdosed on drugs or alcohol on purpose?
3. Burned yourself on purpose?
4. Tried to strangle or hang yourself?
5. Jumped from a high place to hurt yourself?
6. Shot yourself with a gun?
7. Swallowed poisons/caustic sub. on purpose?
8. Asphyxiated or smothered yourself?
9. Tried to drown yourself?
10. Stabbed/punctured yourself on purpose?
11. Banged your head, hit yourself, hit things?
- 12. Went into dangerous cold to freeze yourself on purpose? (AK only?)**
- 13. Drove recklessly on purpose?**
- 14. Walked on the train tracks so a train would hit you?**
- 15. Walked out into the traffic so a car would hit you?**

Changes to Exposure to Suicide Questionnaire



Original Intro:

“Next we would like you to answer some questions about people you have known who attempted suicide and survived or died by suicide.

_____1. How many people have you known who have died by suicide [in your lifetime/in the past year/since your last assessment]?

_____2. How many people have you known who have attempted suicide and survived [in your lifetime/in the past year/since your last assessment]?

Interviewer: if none, skip to next measure. If more than one, complete for the 3 most significant as defined by the participant.”

Revision Based on Phase I Feedback:

No revision needed.

Changes to Exposure to Suicide Questionnaire



Original Follow-up Question:

Person #1 (ask for 3 most significant to participant)

Who was this person? Was he/she a family member or romantic partner, a friend, a coworker, an acquaintance? [Yes or No]

_____ 3a1. Family member or romantic partner

_____ 3a2. Friend

_____ 3a3. Coworker

_____ 3a4. Acquaintance

_____ 4a. INTERVIEWER: if applicable, code type of family member

_____ 4b. INTERVIEWER: if applicable, "Were you blood related?"

1=Mother 2=Father 3=Brother 4=Sister 5=Wife/husband 6=Son/Daughter 7=Grandparent 8=Girlfriend or boyfriend 9=Other family member (e.g., aunt, uncle, cousin)

Changes to Exposure to Suicide Questionnaire



Original Follow-up Questions:

_____ 5a. Did this person die by suicide or attempt suicide and survive?

1=Suicide Attempt 2=Death by Suicide

_____ 6a. How long ago did this happen? (If he or she did it more than once, when was the most recent?)

1=Within the past year / 2=1-5 years ago / 3=6-10 years ago / 4=More than 10 years ago

_____ 7a. On a scale of 1 to 5, where 1 is “not close” and 5 is “very close,” how close would you describe your relationship with this person?

Not close

Somewhat Close

Very Close

1

2

3

4

5

_____ 8a. How much of an effect did this suicide attempt/suicide have on your life?

INTERVIEWER: probe re: how long any effects lasted for the participant and code from categories below

1=The attempt/death had little effect on my life

2=The attempt/death had somewhat of an effect on me but did not disrupt my life

3=The attempt/death disrupted my life for a short time

4=The attempt/death disrupted my life in a significant or devastating way, but I no longer feel that way

5=The attempt/death had a significant or devastating effect on me that I still feel

Revision Based on Phase I Feedback:

****No Need for Revision Noted. Correct?**

Effects of Study Adaptations



- Removal of upper age limit: Nearly half (48%) of the recruited sample was aged 35 years or older.
- Multiple modes of baseline assessment: Phone was used by nearly 60% of participants.
 - 79% during the COVID-19 pandemic
- Multiple modes of intervention delivery: 54% by text message; 29% by postal mail; 17% by email.

Effects of Study Adaptations



- Control Group Intervention: Nearly half (45%) of participants referred to BH treatment; 14% to Financial Assistance; 13% to employment services, 9% to Housing assistance.
- Development of rapport before study procedures: At 12 months, 73% of participants remembered their baseline visit as a “very positive experience”; 19% as “somewhat positive”; and 8% as “neutral”.
- Intensity of intervention delivery: 86% felt there were not enough messages; only 29% felt the messages were sufficient.

Effects of Study Adaptations



- Recruitment strategies: Over half (60%) of participants recruited by the recommended means (FB, radio, flyers, word of mouth); 40% by word of mouth.
- Outcome measures: At baseline, the locally informed methods (driving, cold, traffic) accounted for capturing an additional 911 suicide attempts among over ~130 participants.


Summary



- The goal of the adaptation process for this study was to improve the fit of the features of the study to the characteristics of the communities where it would take place and the people who would participate.
- The community consultation process also altered many other study design features.
 - Broadening eligibility criteria with regard to age and possession of a cellular device.
 - Outcome measure adaptations allowed capture of a wider range of suicidal behavior than otherwise would have.

Summary



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- This experience, and the resulting data, validates the importance of community engagement, and that similar community engagement with the priority population would be beneficial for all intervention research, with any and all populations.

Q&A / Discussion



*Thank-you Waewaenen Tleko Yaw`ko
Gracias Yakoke t'ig'icid Miigwech Ahó
Néá'eshe Mahalo Wado Welalin
Gunalcheesh Niawenh T'ooyaksiy niin
há?n?? cn Gilakas'la Huy tseep q'u*

Eagle/Salmon Artwork by Stuart Pagaduan, Cowichan, First Nations

Thank You!



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