# Trust in community-based participatory research



# Messengers for Health on the Apsáalooke Reservation

#### Messengers for Health

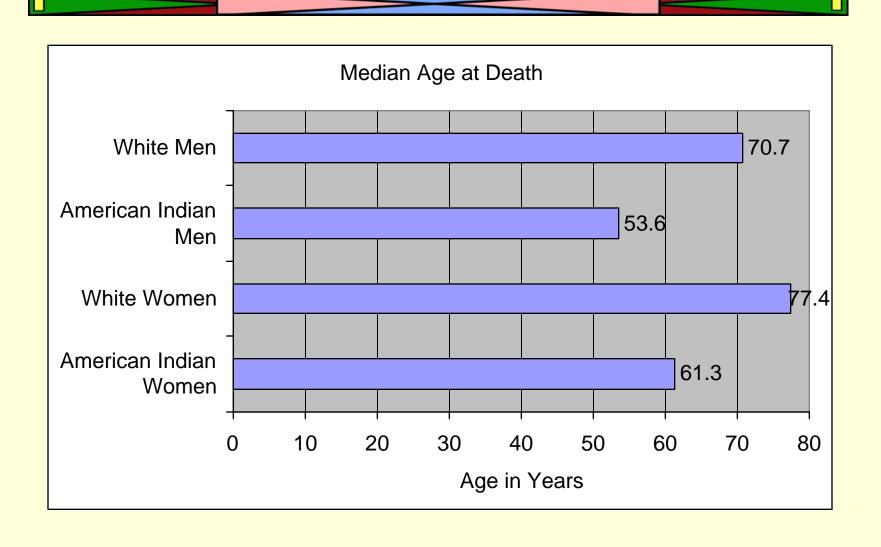
- Current project staff: Alma Knows His Gun McCormick, Suzanne Christopher, Vanessa Watts, Shaleen Old Coyote, Bethany Letiecq, Deb LaVeaux, Neela Bearcomesout, Alacea Head, Rochelle LodgePole, Emmaline Jackson
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- The support of the American Cancer Society is acknowledged with gratitude.

# **Topics**



- Health disparities
- Research with Native Americans
- Research partnership
- Levels of trust

# Health Disparities in Montana

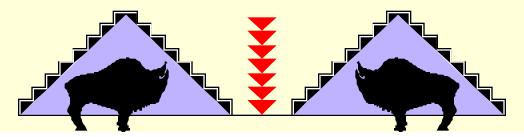


# Excess death rates for Native Americans compared to whites in Montana:

- cancer (42% higher)
- heart disease (29% higher)
- stroke (23% higher)
- infant mortality (100% higher)
- diabetes (291% higher)
- chronic lower respiratory disease
- pneumonia and influenza
- motor vehicle and non-motor vehicle injuries
- suicide

### Why CBPR in Native communities

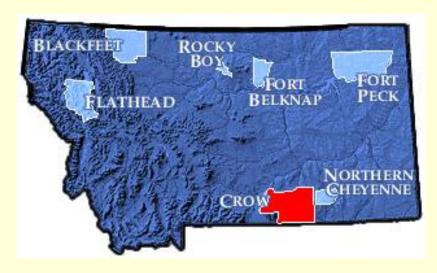
- History, history, history
- Promised study benefits rarely reach communities
- Study results/data not given to community
- Researchers disrespectful of cultural practices
- Studies have harmed communities



## Research Partnership



- Partnership began in 1996
- •Funding began in 2001
- Focus: Cervical health and Indian Health Service



#### 1st level of trust

- Initial academic and community partners
- 5 recommendations
  - Acknowledge background histories
  - Understand broader histories
  - Be present, listen, and receive
  - Acknowledge expertise
  - Be upfront about expectations

#### Acknowledge background histories

- Researchers are influenced by their backgrounds. Including:
  - their histories and the history of their institutions
  - their assumptions and stereotypes
- Continually work toward selfunderstanding and self-reflection

#### Understand broader histories

- History of research between:
  - Specific community and specific institution
  - Between the community and US government
  - Broader history of the community
- Activities used in this project
  - Auditing a course on Montana Indians
  - Reading history books authored by Native people, critiques of Western research, history books on the Crow tribe
  - Having open discussions about past history of research

## Be present, listen, and receive

- Tribal communities are aware when a stranger comes into town.
- Committing to spending time each month at Crow.
- Attending social and cultural events.

## Acknowledge expertise

- Acknowledge both expertise from community and university partners
- Approach community members as equal partners and experts
  - Our academic partner explained intentions to community and asked community how to proceed

## Be upfront about expectations

- Community wants to see university partners who are sincere and honest about their intentions
- Communicate expectations:
  - Publishing and presenting at scientific meetings
  - Allocation of grant money
  - Other duties of university researcher

#### 2nd level of trust

- Between initial partners and greater community and academic setting
- 3 recommendations
  - Do not assume people know the project uses a CBPR approach
  - Revisit first level recommendations with potential new partners
  - Match words and actions

# Do not assume people know the project uses a CBPR approach

- Continually educate others on project history, methods, and partners.
- Choose initial partner wisely—expansion of trust relationship is facilitated by initial partners validating credibility of academic partner.
- Determine different views between and among federal and tribal policy makers.

# Revisit first level recommendations with potential new partners

- No guarantee that trust will transfer to potential new partners.
- Not everyone will want to be part of project when they learn what CBPR entails.

#### Match words and actions

- Our project gave 5 messages
  - We recognize community history
  - Project will directly benefit community
  - Community and academic partner will work together on all phases of the work
  - We will keep the community informed on the progress of the project
  - We will do all we can to continue program indefinitely

#### Results of trust building

- Community sat back and watched and watched and watched.
- Indication that project is trusted:
  - Recognition in community events
  - Male community members asking to develop a project focused on men's health
  - More and more community members wanting to be involved in project

#### Barriers to trust building

- Lack of funding in initial stages
- Distance between university and community
- People from different backgrounds working together (cultural competence)
- Coming to community from academic setting—viewing community members as experts in their own right

#### Conclusion

- Applicable to community members and researchers working in partnership
- Focused on academics
- Level of safety occurs over time—may not always be culturally competent
- Trust—not the only or best way, but was integral to our project

