

Talking Health Literacy



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Partnerships *for* Native Health

Partnerships for Native Health

- Funded and supported by National Institute of Health (NIH)
- P4NH's mission to conduct community-centered research, training, education, and outreach to improve the health and quality of life of American Indian and Alaska Native populations



What is Health Literacy?

The degree to which an individual has the capacity to obtain, communicate, process, and understand basic health information and services to make appropriate health decisions.



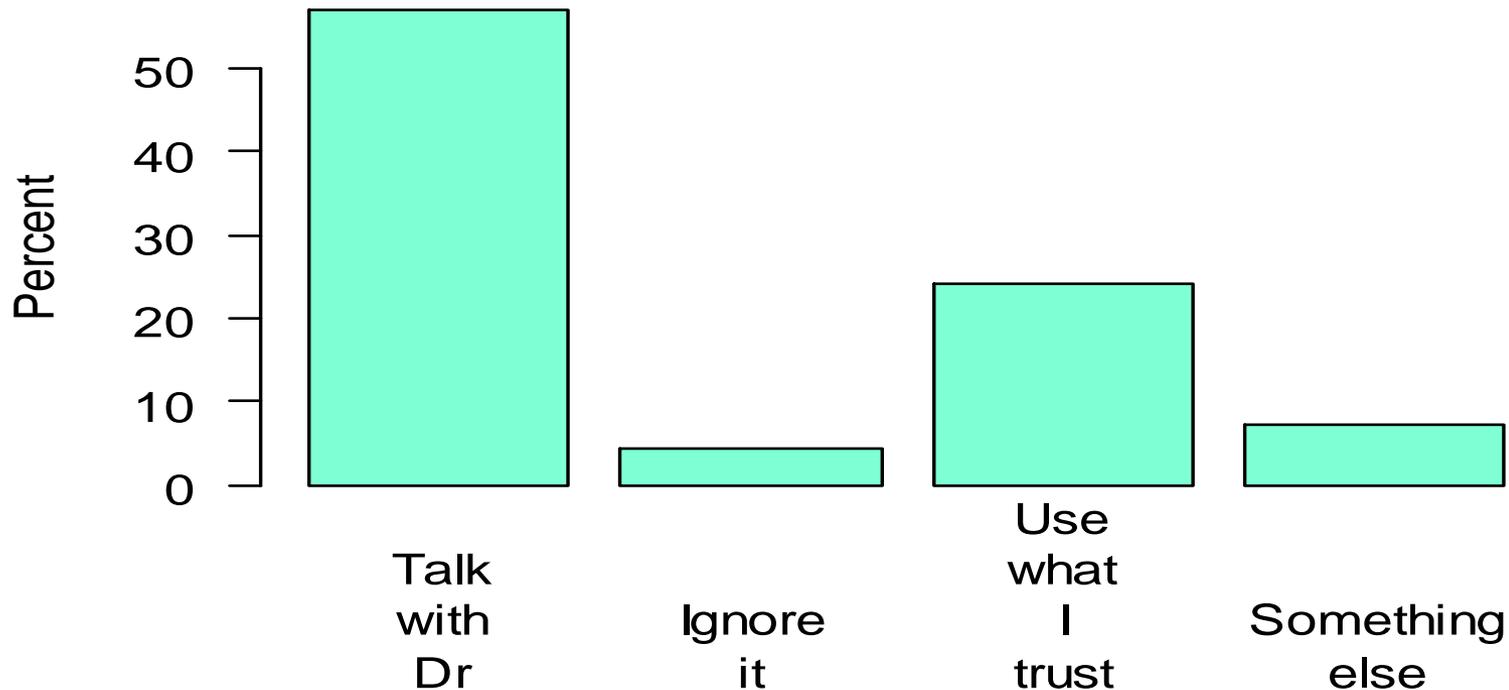
Health Literacy and Health Communication Study



- Surveyed 261 American Indians/Alaska Natives and conducted 4 focus groups in 2 rural and 2 urban tribal communities
- Our questions
 - Where people getting health information
 - What is their confidence in it
 - Where would they like to receive information from
 - What would give them greater confidence in that information?

Survey Results

When your information disagrees with your Doctor:



Focus Group Results



- **Barriers to accessing health information**

Confidentially in rural communities

“There’s always an issue and always a problem [receiving care at the clinic], and then my family’s involved, from the receptionist on up to my co-workers. It’s like everybody knows what my business is and what has happened.”

Readability

“After I got information from the doctor, the language was what I [was] having [trouble with].”

Lack of knowledge of how to use health insurance

“I think we need to get used to having insurance. I don’t think we are utilizing it as well as we can as individuals. I think we’re still stuck in the IHS system.”



- **Where are they getting health information?**

Online and social media

“Well, I don’t know that I trust the information, but I just—I go online and like this myself, personally, it’s what I had to—it’s what I did. It helped me with asking questions”

“Sometimes [the health care providers] said, there’s not good information [on the internet], but I don’t know how you would tell the good from the bad.”

Family members

“I think it’s very important that my children-they need to know the family health history on both sides and talk about what's going on with our health.”



- **Where do they want to get health information from?**

Digital Storytelling

“Most of them are like personal stories... they’ve actually had a disease and they tell about the process...but I would pay more attention if they were Native people

Culturally attuned and health literate providers

“It was very frustrating because I didn’t know what they were tryin’ to explain to me, and it took a while to—I had to go see several doctors before I ever figured it out”

Community health workers and traditional healers

“My dad used pitch-he made pitch juice with....the willow buds that’s coming out now. He boiled it up and stuff and we used it for colds and everything...and we still use it.”

Case Study 1



A Targeted Approach to Increasing American Indian
Organ Donation

Overview



- Project Background
- Focus Groups
- Results
- Campaign Materials & Events
- Zip code data
- Project Status

Chronic Disease and Kidney Failure

- 
- American Indians suffer from disproportionately high rates of diabetes and kidney disease ¹
 - Diabetes is the leading cause of kidney failure ²
 - Among persons with advanced kidney disease, only transplantation increases long term survival ³
 - Compared with Whites, AI/AN are less likely to receive kidney transplants, and wait twice as long for transplantation ^{4,5}

Organ Donation

- 
- Rates of consent for deceased donation in AI/AN are lower than in the general population ⁶
 - 1% of candidates awaiting transplants are American Indian or Alaska Native, only 0.3% of all organ donors are American Indian or Alaska Native ⁷
 - Unique cultural and spiritual considerations
 - Mistrust of health care system

Project Specific Aims



Aim 1: Examine knowledge, attitudes, and behaviors regarding organ donation and transplantation among tribal college students

Aim 2: Develop culturally tailored media materials to heighten awareness about need for donation and benefits of transplantation

Aim 3: Increase the number of American Indians and Alaska Natives who become organ donors

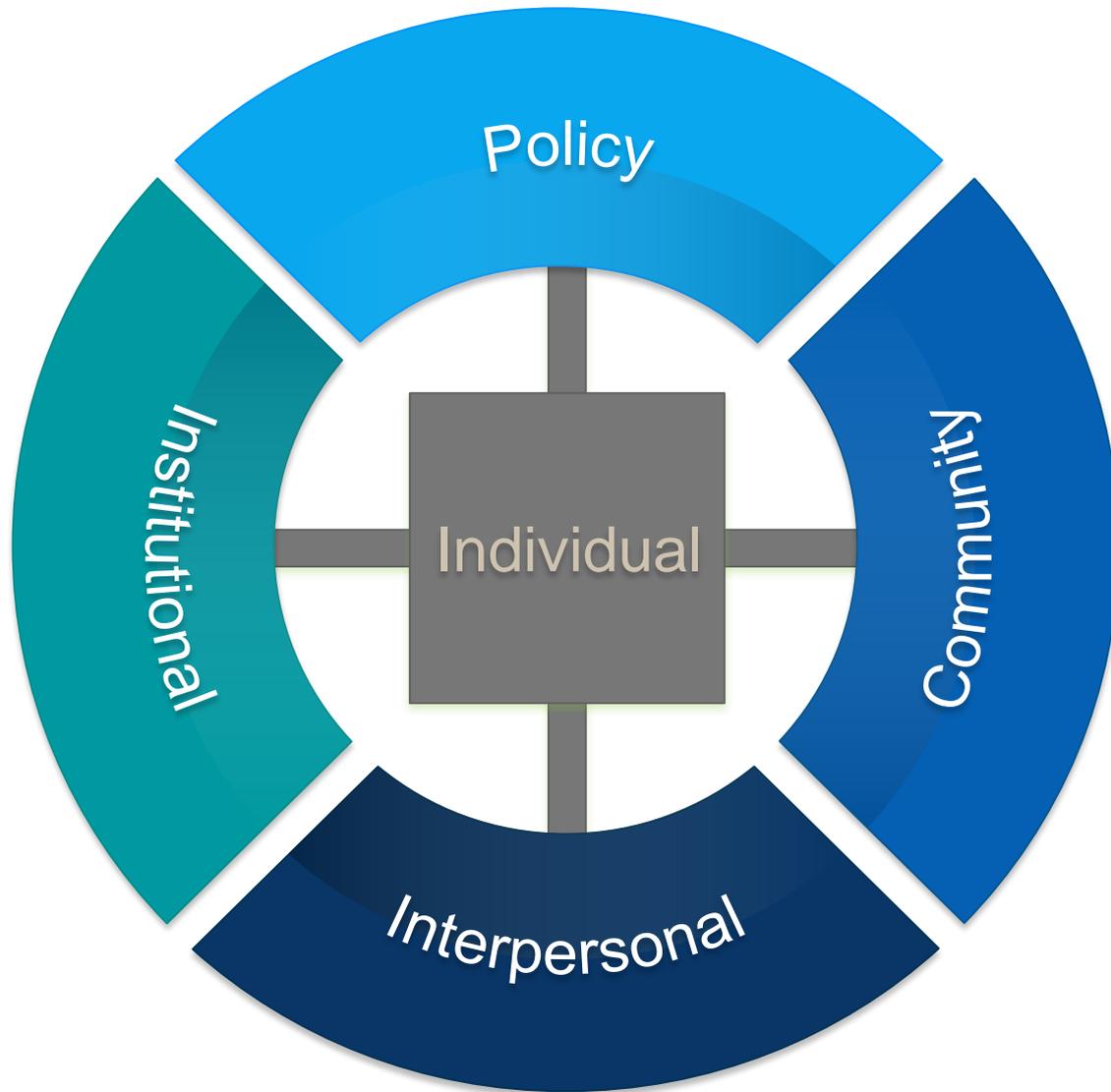
Ecological Model



“An ecologic or population health model emphasizes the importance of the social and physical environments that strongly shape patterns of disease and health as well as our responses to them over the entire life cycle.”

(Fielding, Teutsch, Breslow, 2010)

Ecological Model

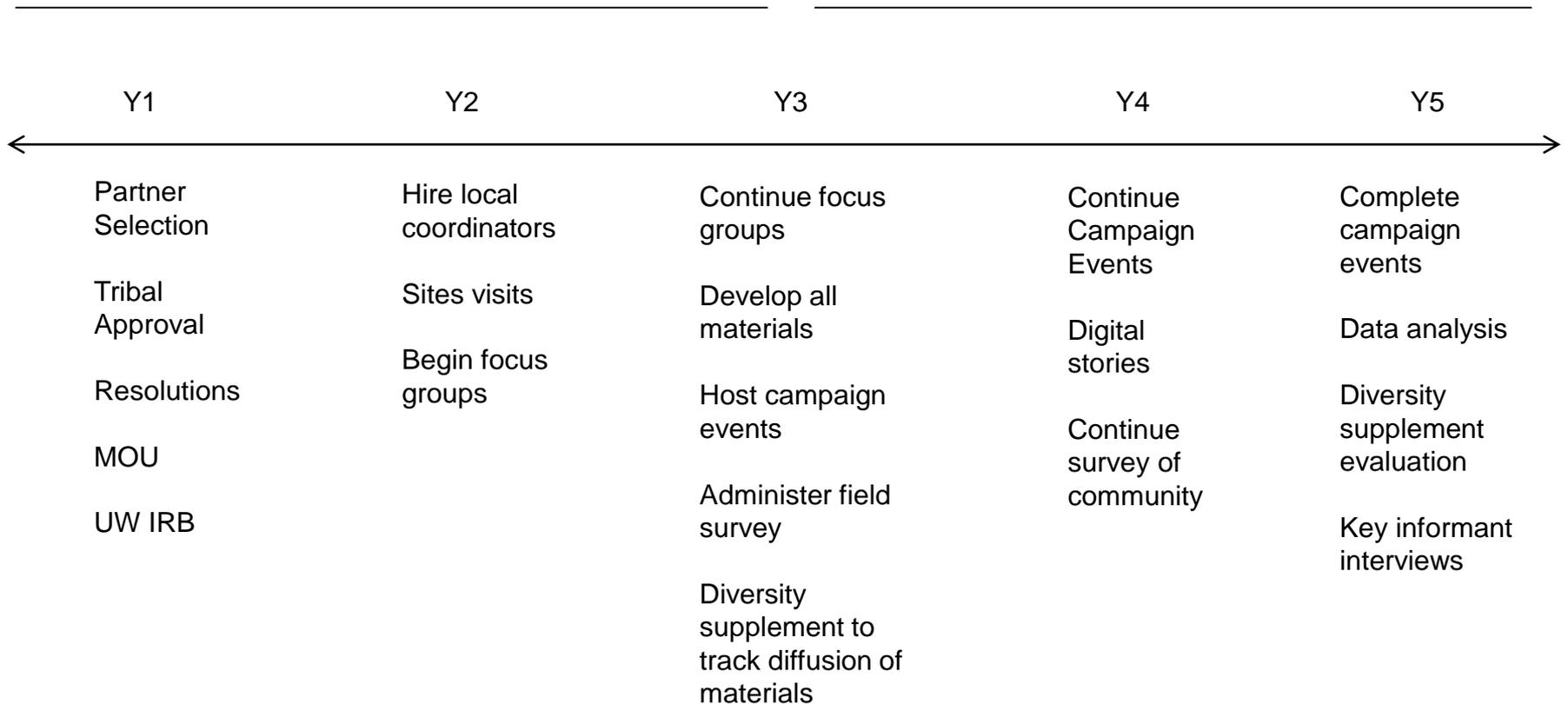


Timeline of Study



Phase 1

Phase 2



Partner Sites

- 
- Partner sites were selected according to three criteria:
 - Level of interest in becoming a partner
 - Identification of faculty liaison to act as site coordinator
 - Established health program to host the project



AMERICAN INDIAN
HIGHER EDUCATION CONSORTIUM

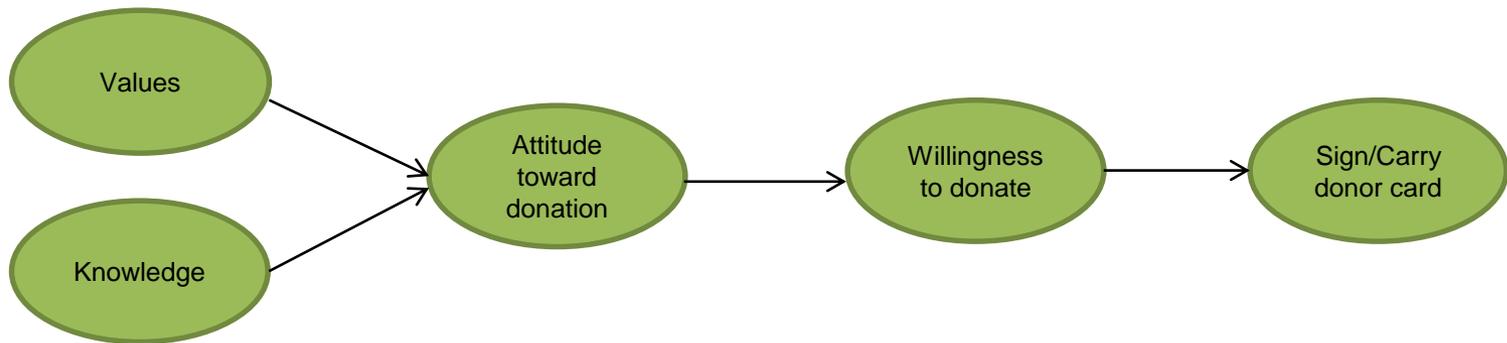


Focus Groups



Framework

- The organ donor willingness model (ODWM) ⁸ guided the focus group discussion and questions.
- The ODWM considers individual knowledge, attitudes, beliefs and behaviors as determinants of willingness to become an organ donor.



Discussion Themes

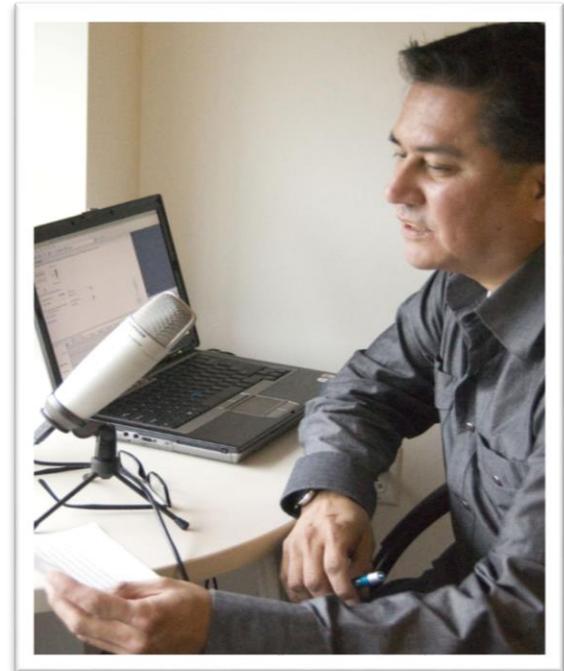
- 
- Knowledge of organ donation and transplantation
 - Perceptions of community need
 - General beliefs about doctors and medical system
 - Spiritual and religious beliefs
 - Plans on willingness to donate
 - Attitudes regarding the family's role
 - View of existing organ donation materials

Recruitment

- 
- Recruitment carried out by local site coordinators
 - 99 participants recruited at tribal colleges by flyers, campus announcements, classroom presentations
 - Eligibility criteria
 - American Indian or Alaska Native
 - 18 years or older
 - Affiliated with the tribal college (student, staff, faculty)

Analysis

- Descriptive content analysis
- Independent review of transcripts by 5 members of project staff
- Identified themes within and across focus groups coded into 4 categories
 - knowledge
 - attitudes
 - beliefs
 - behaviors





Results

Focus Groups and Participants



Tribal College	Date	Attendance
Northwest Indian College	12/12/2008	8
Northwest Indian College	5/20/2009	16
United Tribes Technical College	10/22/2008	10
United Tribes Technical College	1/24/2009	9
Turtle Mountain Community College	1/23/2009	6
Turtle Mountain Community College	4/28/2010	16
Fort Peck Community College	7/14/2009	9
Fort Peck Community College	2/26/2010	13
Blackfeet Community College	2/18/2010	7
Blackfeet Community College	3/11/2010	5
TOTAL		99

Knowledge

- 
- Community knowledge drawn from direct family experience with chronic illness
 - Participants with family members on dialysis or with advanced kidney disease were knowledgeable about medical benefits of organ donation and medical process (e.g., referral, donor waitlist)

“..there’s a lot of people on the reservation that do have diabetes and that probably later on in life – with their diabetes – will be on dialysis. So I think it’s going to be a big part of our health plan, that we have to figure on that becoming a bigger problem.”

Knowledge (cont'd)

- 
- Knowledge of the process required to become an organ donor (registration) varied across participants.

“People just have a vague idea of organ donation. You know, it’s not really advertised.”

“Just because it says on your license doesn’t mean that you are going to donate. You fill out a thing, some kind of application to donate.”

“There’s not a lot of information in this community about organ donors just for the fact that the religion most people carry here is, you just don’t do it.”

Knowledge (cont'd)

- 
- Pathways to learning about organ donation were discussed. Television and movies were the two primary sources of information.

“I’ve seen it on TV. They advertise with it. To promote bone marrow....I’ve never actually tried to investigate on the reservation what kind of organs they want.”

“Yeah, I’ve seen on TV. Are you familiar with House? That show.”

“That movie, My Sister’s Keeper.....whatever this little girl needed, they could get it from her sister and she was pretty much born to donate to her sister – to keep her alive”

Attitudes

- 
- Attitudes discussed in context of family's role in decision making process
 - willing to honor written or clearly communicated requests of family members
 - unwilling to donate family member's organs in absence of clear instructions of deceased person's wishes

“...when my brother passed away – you know he was perfectly healthy and everything – and when the doctors asked if we wanted to donate his organs, we said no. I think that if you want to be an organ donor you should fill out the application and make it aware to your parents.”

Beliefs

- 
- Non-biomedical, culturally based beliefs about organ donation were often attributed to elders or people described as “traditional”
 - Participants described traditional beliefs as commonly held, but they were not necessary pervasive among participants themselves.

“ well most Indians around here believe that Indians should go back to the ground with what they were born with.”

“I think it’s morally right to donate your organs. It’s really good...whether they be agreeing with traditional values or not. It’s the right thing to do. That’s the bottom line.

Beliefs

- 
- Beliefs about the health care system were similar across sites.
 - Higher levels of distrust associated with decreased willingness to become an organ donor
 - Perceived inadequacies in health care quality and access

“Well, we were just saying how it’s more or less IHS doctors up here but maybe if it was in [large city named] or any other place I would definitely trust the doctors”

“A lot of the health care we get up here isn’t up to standards, I believe, because of the tight budget.”

Behaviors

- 
- Most participants reported a living donation to a family member or friend was an acceptable form of organ donation.

“I think that I wouldn’t want to be a donor. But I guarantee you, if my brother needed it – and my family knows that. No matter what my beliefs are on me, I’m always willing to put my family before me.”

“To me, if I ever donated an organ, I think it would have to be a really close person like my kids, or something.”

Behaviors

- 
- Among participants unwilling to become organ donors, concerns about being healthy enough and adhering to a healthy lifestyle emerged

“I don’t think I would because...I know you have to have a certain lifestyle for that – to keep your immune system up and healthy. But not everybody can. I sure can’t keep healthy.”

Discussion

- 
- Clear patterns of family-level decision making emerged across focus group sites
 - Direct family experience with chronic illness associated with increased knowledge of medical benefits of donation
 - Findings confirmed that attitudes about organ donation and transplantation are influenced by cultural beliefs.
 - Mistrust of the health care system must be considered in future health campaigns, along with future research of the message interference that may take place as a result

Campaign Events



Campaign Events by Site



Tribal College	On campus	Off campus	Total Events
Turtle Mountain Community College	5	4	9
United Tribes Technical College	4	0	4
Blackfeet Community College	3	19	22
Fort Peck Community College	3	8	11
Northwest Indian College	8	3	11
Total			57

Campaign Materials




Giving Life A Second Chance

Register as an Organ, Eye and Tissue Donor

More than 900 American Indian and Alaska Native people in the U.S. are on the waiting list for organ and tissue transplants, and 300 more are added each year. But there were only 68 American Indian and Alaska Native donors in 2008. It takes only one donor to save or improve the lives of 50 people.

You can help today!
Register as a donor online or in person at the Department of Motor Vehicles.
Talk with your family about your decision to donate.

For more information visit www.DonateLifeToday.com
or call 1-877-275-5269.





Giving Life

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The Gift

One Paddle · One Mind · One Family

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Campaign Materials




We Are All United

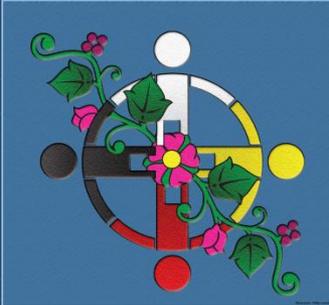
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or call 1-804-782-4920

United Tribes Technical College UNIVERSITY OF WASHINGTON NIDDK



We Are All United

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Turtle Mountain Community College UNIVERSITY OF WASHINGTON NIDDK



Giving Life

Register as an Organ, Eye, and Tissue Donor

More than 900 American Indian and Alaska Native people in the U.S. are on the waiting list for organ and tissue transplants, and 300 more are added each year. But there were only 68 American Indian and Alaska Native donors in 2008. It takes only one donor to save or improve the lives of 50 people.

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Register as a donor online or in person at the Department of Motor Vehicles.
Talk with your family about your decision to donate.

For more information visit www.DonateLifeToday.com
or call 1-877-275-3269.

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Campaign Materials



The Gift

Register as an Organ, Eye & Tissue Donor

More than 900 American Indian and Alaska Native people in the U.S. are on the waiting list for organ and tissue transplants, and 300 more are added each year. But there were only 68 American Indian and Alaska Native donors in 2008. It takes only one donor to save or improve the lives of 50 people.

You can help today!

There are two ways to help... Register as an organ, eye, and tissue donor. Be a living donor and share an organ with a family member or a friend in need.

Register as a donor online or in person at the Department of Motor Vehicles. Talk with your family about your decision to donate. For more information visit www.DonateLifeToday.com or call 1-877-275-5269.

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Source: <http://open.transplant.fda.gov/foia/Data/foiaData.asp>
This work is funded by the National Institutes of Health
Grant No. R01 DK072670



For more information visit www.DonateLife.net or call 1-804-782-4920

To learn about diabetes, kidney disease, organ donation, and transplants visit <http://www2.niddk.nih.gov>

"Two years ago I went through a gastric bypass to control diabetes, but they can't reverse the damage to my kidneys. I'll be a future recipient. I don't think that we, as diabetics, think about what it's going to be like ten years down the road."

Wannetta Bennett
Turtle Mountain Chippewa

A special thank you to the donors, recipients, and community members dedicated to increasing awareness of the need for organ donors.

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Turtle Mountain Community College

We Are All United

Register as an Organ, Eye, and Tissue Donor

www.DonateLife.net
1-804-782-4920



There are two ways to help... Register as an organ, eye, and tissue donor. Be a living donor and share an organ with a family member or a friend in need.

How can I register as an organ, eye, and tissue donor?
To become a registered donor, complete and mail in the attached form. You can also register online at www.DonateLife.net or in person at the Department of Motor Vehicles. Remember to talk with your family about your decision to donate. For more information call 1-804-782-4920.

Who can donate?
Everyone can be a registered donor.

Who will get my organs?
Organ Procurement Organization coordinators match your organs to people on the waiting list based on medical urgency, length of time on the waiting list, tissue type, blood type, and body size.

What organs and tissues can be donated?
Organs that you can donate are heart, kidneys, pancreas, lungs, liver, and small intestine. Tissues that you can donate are corneas, bone, blood vessels, veins, nerves, heart valves, skin, tendons, and ligaments.

When are organs recovered from the body?
If you are sick or injured and admitted to the hospital, the number one priority is to save your life. The doctor in charge of your care has nothing to do with transplantation. Recovery of organs and tissues can only be considered after a doctor declares you have passed away.

How can I donate an organ to a family member or friend?
To find out if you can be a living donor call Donate Life Today at 1-804-782-4920 and request a list of local transplant centers. Call the transplant center and an independent donor advocate will help you through the evaluation and decision-making process.

Who can donate?
In general, to be a living donor you must be physically fit and in good health. You will get a blood test to determine if your blood type is compatible with the recipients.

What organs and tissues can be donated by a living donor?
You can donate one of your two kidneys, or part of your liver, lung or intestine. You can donate blood, bone marrow, blood stem cells, and umbilical cord blood.

When are organs removed from the body?
If you choose to become a living donor, the transplant surgery is scheduled through the local transplant center at a time that is convenient for you and the recipient.

More than 900 American Indian and Alaska Native people in the U.S. are on the waiting list for organ and tissue transplants, and 300 more are added each year. But there were only 68 American Indian and Alaska Native donors in 2008. It takes only one donor to save or improve the lives of 50 people. You can help today! Register as an organ, eye, and tissue donor.

Survey Overview

- 1,231 surveys collected
- 16-items
- Demographics: age, education, marital status
- Family history
- Attitudes about chronic illness
- Donor registration intention
- Type of materials seen and ranking of influence

#

The Gift of Life Project

Date: / /
Mo day year

Please fill out the survey below by marking an in the box. Mark only one response for each question unless otherwise instructed. Thank you for filling out this survey!

1. Did you register to be an organ donor or sign a donor card today?
 Yes
 No
 I am already registered
2. Are you considering registering to be an organ donor or signing a donor card?
 Yes
 No
 I am already registered
3. Do you intend to discuss organ donation with your family?
 Yes
 No
 I have already discussed organ donation with my family
4. Which organ donation materials have you seen? (check all that apply)
 Brochure Poster Bookmark Digital video story Other _____
5. How much do you think each of the following approaches would influence a person's decision to register as an organ donor?

	A lot	A little	Not at all
a. Written materials (brochure, poster, bookmark)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Digital video stories	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Talking with family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Talking with project staff	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Other _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please answer the following questions about yourself:

	Yes	No	Don't Know
6. Do you have serious kidney disease?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Does your mother or father or sibling(s) have serious kidney disease?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Do you know anyone close to you who is on kidney dialysis?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Do you have diabetes?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Does your mother or father or sibling(s) have diabetes?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	I already have diabetes	Strongly agree	Somewhat agree	Somewhat disagree	Strongly disagree	Don't Know
11. I will probably get diabetes some time in my lifetime.	<input type="checkbox"/>					
12. There are things I can do to prevent diabetes.	<input type="checkbox"/>					

13. Do you have children? Yes No

14. How old are you?
 19 years or under 20-29 years 30-39 years 40+ years

15. What is the highest level of education you have had?
 Some high school High school
 Current college student Completed college degree
 Graduate School Technical/vocational school

16. What is your sex? Female Male

17. What is your marital status?
 Married/Partnered Single Separated/Divorced Widowed

Demographics



Variable	N = 1,231	%
Age		
19 years or less	265	22
20 - 29 years	265	22
30 - 39 years	235	20
40 years or more	440	36
Sex		
Female	743	62
Male	456	38
Children*	758	66

*A total of 758 respondents reported having children

Demographics



Variable	N = 1,231	%
Education		
Some high school	91	8
High school	346	29
Current college student	240	20
Completed college degree	321	27
Technical or vocational school	62	5
Graduate school	140	12
Marital Status		
Single	581	46
Married/partnered	510	42
Separated/divorced	110	9
Widowed	34	3

Family History and Attitudes



Family History	N = 1,231	%
Family member with serious kidney disease	121	11
Someone close to you on dialysis	327	29
Family member with diabetes	521	46
Personal History		
Has serious kidney disease	45	4
Has diabetes	150	13
Attitudes		
Will probably get diabetes sometime in my life*	347	37
I can prevent diabetes*	961	90

*respondents strongly agree or somewhat agree

Ranking of Materials



How much do these influence a person's decision to register as an organ donor?	A lot %	A little %	Not at all %
Written materials (posters, brochures)	47	44	9
Digital videos	57	33	11
Talking with family	63	27	9
Talking with project staff	54	34	12
Other	44	27	29

Donor Registration Intention



Response	N = 1,231	%
Already registered an organ donor	288	23
Registered as donor today	185	15
Considering registering	238	19
Not considering	517	42
Intend to discuss organ donation with family	490	41
Have already discussed organ donation with family	219	18

Donation Groups



Survey Item	Not Considering N = 517	Considering N = 238	Registered at Event N = 185	Already Registered N = 288	P Value
Will or have discussed organ donation with family	142 (28%)	179 (76%)	143 (81%)	243 (87%)	<.0001
Ranking of Influence					
Written materials*	174 (38%)	112 (52%)	96 (60%)	136 (51%)	<.0001
Digital stories*	178 (42%)	133 (64%)	91 (62%)	185 (70%)	<.0001
Talking with family member*	208 (50%)	141 (67%)	111 (72%)	207 (76%)	<.0001
Talking with project staff*	205 (50%)	141 (67%)	111 (73%)	207 (76%)	<.0001

* Response = A lot

Predictors of Organ Donation



Survey Item	Not Considering N = 517	Considering N = 238	Registered at Event N = 185	Already Registered N = 288	P value
College or higher education	184 (37%)	81 (35%)	108 (59%)	148 (52%)	<.0001
Has children	291 (61%)	133 (59%)	126 (77%)	206 (76%)	<.0001
30 years old or more	268 (53%)	97 (42%)	125 (69%)	183 (64%)	<.0001

Zip Code Registry

- Were able to track local changes in the number of donors by zip code (obtained from Living Legacy and donor registries) for some partner states.
- The zip code tables show pre-intervention donor consent counts (2009), followed by donor consent counts during the intervention of the health messaging campaign (2010-2012).
- Note: Intervention peeked in late 2010-2011

Northwest Indian College

Northwest Indian College Surrounding Zip Codes

Zip Code	2009	2010	2011	2012
98513	400	1253	1344	338
98327	113	394	517	114
98433	226	791	861	223
98501	441	1395	1585	341
98503	407	1362	1493	320
98504	18	21	6	1
98507	27	92	79	12
98508	0	9	0	0
98509	0	1	0	2
98516	252	777	874	213
98540	0	2	1	0
98558	2	15	13	5

Fort Peck Community College

Fort Peck Community College Surrounding Zip Codes

Zip Code	2009	2010	2011	2012
59255	18	40	60	16
59201	25	73	109	39

Blackfeet Community College

Blackfeet Community College Surrounding Zip Codes

Zip Code	2009	2010	2011	2012
58385	0	0	0	0
59417	28	55	86	34
59427	32	74	114	34

Project Status

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- Back to our Ecological Model – continuing our work with partner communities.
 - Project expanded into the tribal dialysis centers in new round of funding (2012-2017)
 - Targeted donation focus

Acknowledgments

National Institute of Diabetes and Digestive
and Kidney Diseases RO1 DK079670

Participating Tribal Colleges

LifeCenter Northwest

Community members

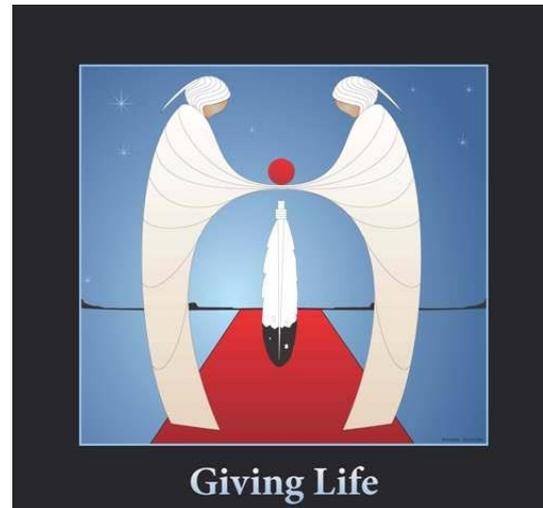
Artists and project staff



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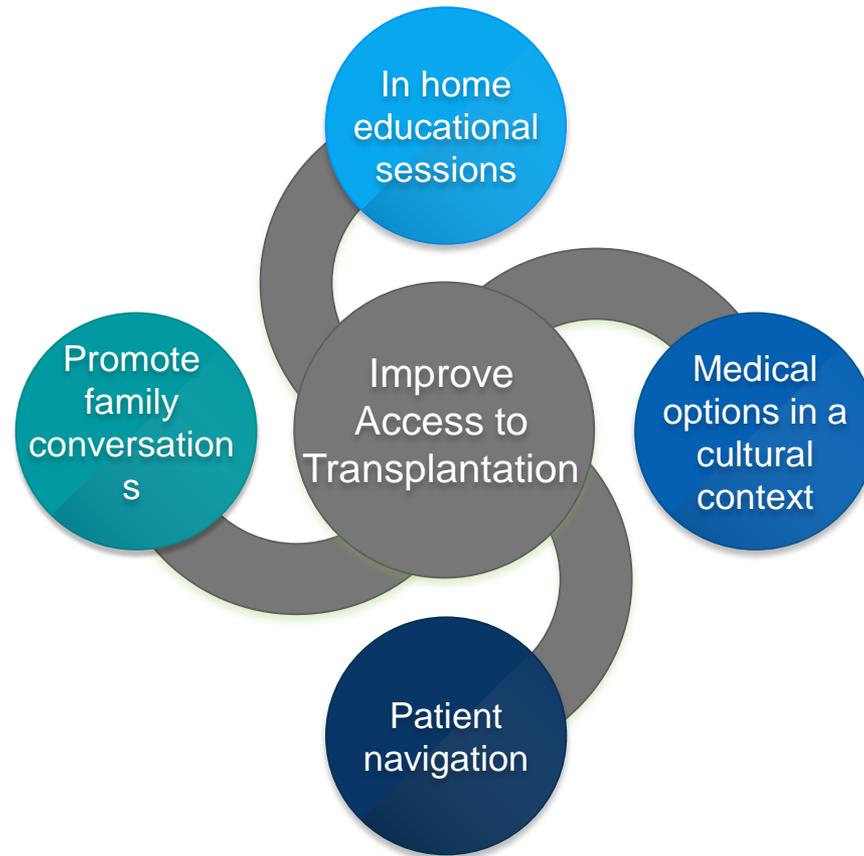
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Case Study 2



Culturally Adapted Strategies to Enhance Kidney Donations in Native Communities

Core Intervention – House Calls Plus



The “CAS” Project

House Calls Plus



- ❖ Welcome family and friends
- ❖ Read verbal consent form to guests
- ❖ Family and friends complete the pre-test
- ❖ Conduct the House Calls educational session on Living Donor Kidney Transplant
- ❖ Share Digital Stories
- ❖ Family and Friends Complete the post-test
- ❖ Give out incentives to Family and Friends
- ❖ Thank everyone for coming.

The “CAS” Project

After the House Calls....

- ❖ Dialysis Patient completes survey 1 week post House Calls
- ❖ Dialysis Patient completes survey 6 weeks post House Calls
- ❖ Community Health Educator contacts dialysis patients every 1-2 months to check on progress on transplant wait list
- ❖ Community Health Educator provides patient advocacy assistance

The Challenge

Pretty straightforward, right?

Not exactly.

Starting to Communicate



- ❖ Social Workers: Busy People, Can they ID AI/ANs, Who is telling what story,?
- ❖ Dialysis Center waiting room: Does it work?
- ❖ Beginning the relationship
- ❖ Be attuned and respectful every step of the way

Continuing the Relationship: Let's Schedule a House Call!

- ❖ Large group or small group --- it is an event!
- ❖ Make guests comfortable.
- ❖ Roll with the flow.
- ❖ Explain about research fidelity.
- ❖ Every guest receives a curriculum and a digital story dvd.

Culturally Adapted



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**HONOR THE GIFT OF LIFE
DONATE A KIDNEY**

**Part Two
Living
Donation**

In Part 2, we will talk about:

- Living Kidney Donation
- Risks for Donors
- Benefits for Donors
- Deciding to Donate
- Donor Evaluation Process
- The Transplant Procedure



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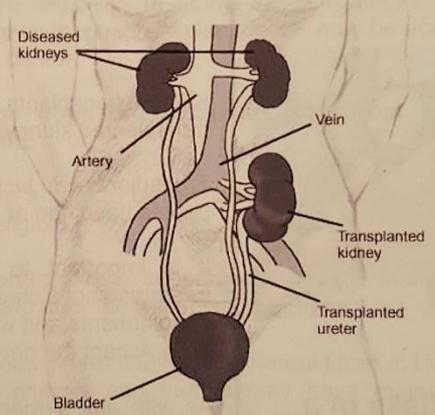


**HONOR THE GIFT OF LIFE
DONATE A KIDNEY**

**Dialysis
is a lifesaving
treatment**

Dialysis is a lifesaving treatment, but it can only do a small part of the work of a healthy kidney.

Kidney transplantation is an operation that places a healthy kidney from another person into your body. This one new kidney takes over the work of the two failed kidneys.



**One new kidney
takes over the
work of two
failed kidneys!**

Insights



❖ Persistence

❖ Respect their decisions

❖ Restraint

❖ Support them where they are at

❖ Advocate

❖ Need to have health literacy at all levels

❖ Community support

Discussion 😊

- 
- What are some the barriers to health communication in your community? What's worked and what didn't work?
 - What is the hardest information to get out to your community? How have you addressed this?
 - Are your providers communicating well with their patients? Are they trained to do this?
 - What are your experiences in accessing culturally appropriate health materials? Do you have access or have you made your own?

Digital Story Training Resources



<http://ndigidreams.com>

<http://www.storycenter.org>

<http://www.npaihb.org>

Thank you!

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