

Study Title: Seasons of Care: Improving Native American Elder Access to and Use of Healthcare through Effective Health System Navigation

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“Seasons of Care” Informed Consent Form Native American Elders

Study Title: Seasons of Care: Improving Native American Elder Access to and Use of Healthcare through Effective Health System Navigation

Dr. Cathleen Willging, a Senior Research Scientist at the Pacific Institute for Research and Evaluation (PIRE) is undertaking a research study that is funded by the National Institute on Minority Health and Health Disparities. This study has been reviewed and approved by the Southwest Tribal Institutional Review Board (IRB).

This is a research study to understand how to improve health insurance and health care for Native American elders (age 55+). Please take your time to make your decision about participating.

You are invited to take part in this study because you are a Native American elder who uses health insurance and health care.

Why is This Study Being Done?

This research is being done because Native American elders often suffer from poor health and have a hard time getting good health care and paying for health care.

The purposes of this study are to:

- Understand how Native American elders use health insurance and health care.
- Understand the reasons that Native American elders have a hard time getting health insurance or health care.
- Train patient navigators who will help Native American elders learn about and use health insurance and health care.

How Many People Will Take Part in the Study?

About 144 people will take part in the study.

What is Being Asked of Me?

- In this study, you will be asked to take part in 1 interview with 2 members of our research team. One member will be a Native American elder who can speak and understand your Native language. You will be asked questions about:
 - Your experiences with health insurance and health care
 - What you know about health reforms like the Patient Protection and Affordable Care Act (or Obamacare)
 - Your opinions about how to improve health insurance and health care for Native American elders

- Some personal information, such as your birth year and income, that will help us compare your experiences with others
- The interview will take about 60 to 90 minutes. We will do the interview in a place where you feel safe and comfortable. If you prefer, we can do part of the interview today and complete it on another day.
- You can choose to do the interview in English or in your Native language.
- If you prefer to do the interview in English, it will be audio-recorded in order to make sure that all the information you provide is correctly written. If you prefer to do the interview in your Native language, the researchers will not record you but they will take notes in English.
- You can refuse to answer any question at any time. You may ask to have the audio recorder turned off at any time. You may ask for the Native American elder researcher to leave the room at any time. You will not be identified by name during the interview or on any paper or audio-recording in the study. All information gathered during the interview will be written on a paper using a code and not your name.
- The information you provide will be entered into a computer that is protected with a password. The information and audio-recordings will be stored in a locked cabinet behind a locked door, but your name will not be linked in any way to this information. The audio-recordings will be destroyed when this study is finished.
- We may also contact you at a later date to participate in a separate activity related to the study.

How Long Will I Be in the Study?

We would like to interview you once, but we may also contact you at a later date to participate in a second activity related to the study. You can decide to stop taking part in the study at any time. If you decide to stop taking part, we ask that you tell the researcher.

What Are the Risks of the Study?

Some of the questions asked by the interviewer may make you feel uncomfortable. If this happens you can talk to the interviewers about it and you can choose not to answer any question that you do not want to. Despite our best efforts to preserve your confidentiality, information you give us may be associated with you. Such information could potentially embarrass you or affect your reputation in the event of a breach of confidentiality.

Are There Benefits to Taking Part in the Study?

There is no direct benefit to you for taking part in this study.

If you wish, you will receive a fact sheet with information about health insurance and health care options for Native American elders and phone numbers of individuals who may be able to answer questions about your health insurance and health care. In addition to having an opportunity to express

your opinions, you and others may benefit from the answers you provide because we will use this information to create a program that we hope will improve healthcare for Native American elders.

What About Confidentiality?

Efforts will be made to keep the personal information in your research record private and confidential. However, we cannot guarantee total privacy. Your personal information may be shared with others if required by applicable law or regulation, such as to report suspected child or elder abuse or neglect. Representatives from the Southwest Tribal Institutional Review Board that oversees research with human subjects may be permitted access to your records. However, your name will not be used in any published reports about this study.

What Are the Costs?

There are no costs to you for participating in this study.

You will be paid \$25 for participating in this interview.

What Are My Rights as a Participant?

Taking part in this study is voluntary. You do not have to answer questions that make you feel uncomfortable, or that you do not wish to answer. You may choose not to take part and you may choose to leave the study at any time. No one but the researcher will know if you decide not to participate. Nothing bad will happen to you if you decide not to participate.

Whom Do I Call if I Have Questions or Problems?

If you have any questions about the study, contact the Principal Investigator, Dr. Cathleen Willging at (505) 765-2328 or by email at CWillging@pire.org. You may also call the study coordinator, Patti Hokanson, at (505) 765-2325 or email her at PHokanson@pire.org.

If you have questions about your rights as a research participant you may call Rachell Tenorio, Southwest Tribal IRB Coordinator at (505) 764-0036. The IRB is a group of people who provide independent oversight of safety and ethical issues related to research involving human participants. For more information, you may also access their website at http://www.mynarch.net/SW_Tribal_IRB.aspx.

You will receive a copy of this form.

You can get a full copy of the study plan (research protocol) by asking the person interviewing you.

Signatures:

I agree to take part in this study.

I agree to allow this interview to be audio-recorded.
 I do not agree to allow this interview to be audio-recorded.

Printed Name of the Participant _____

Signature of the Participant _____

Date _____

Printed Name of the Person Obtaining Informed Consent_____

Signature of the Person Obtaining Informed Consent _____

Date _____

Date _____



“Seasons of Care” Informed Consent Form Outreach Workers and Healthcare Providers

Study Title: Seasons of Care: Improving Native American Elder Access to and Use of Healthcare through Effective Health System Navigation

Purpose:

Dr. Cathleen Willging, a Senior Research Scientist at the Pacific Institute for Research and Evaluation (PIRE), is undertaking a research study that is funded by the National Institute on Minority Health and Health Disparities. This study has been reviewed and approved by the Southwest Tribal Institutional Review Board (IRB).

This is a research study to understand how to improve health insurance and health care for Native American elders (age 55+). Please take your time to make your decision about participating.

You are being invited to take part in this study because you participate in the provision of health insurance and/or health care to Native American elders.

Why is This Study Being Done?

This research is being done because Native American elders often suffer from poor health and have a hard time getting good health care and paying for health care.

The purposes of this study are to:

- Understand how Native American elders use health insurance and health care.
- Understand the reasons that Native American elders have a hard time getting health insurance or health care.
- Train patient navigators who will help Native American elders learn about and use health insurance and health care.

How Many People Will Take Part in the Study?

About 144 people will take part in the study.

What is Involved in the Study?

- This study includes a **survey** about:
 - Your demographic information
 - Your work experience
 - Your experience with health reforms, including the Patient Protection and Affordable Care Act (ACA).
- This study also includes an **interview** about:

- Your work roles and responsibilities relating to Native American elders
- Workplace factors that affect your work with Native American elders
- The effects of the ACA and other health reforms on your work and on Native American elders
- The challenges you face communicating health-related information to Native American elders.

Procedures:

- In this study, you will be asked to take part in a survey and interview with a member of our research team. You will be asked questions about your work with Native American elders related to their health insurance and health care.
- The survey and interview will take about an hour. We will do the interview in a place where you feel safe and comfortable.
- The interview will be audio-recorded in order to make sure that all the information you provide is correctly written. You can refuse to answer any question at any time. You may ask to have the tape recorder turned off at any time. You will not be identified by name during the interview or on any paper or audio-recording in the study. All information gathered during the interview will be written on a paper using a code and not your name.
- The information you provide will be entered into a computer that is protected with a password. The information and audio-recordings will be stored in a locked cabinet behind a locked door, but your name will not be linked in any way to this information. The audio-recordings will be destroyed when this study is finished.
- We may contact you at a later date to participate in a separate activity related to the study.

How Long Will I Be in the Study?

We would like to interview you once, but we may contact you at a later date to participate in a separate activity related to the study. You can decide to stop taking part in the study at any time. If you decide to stop taking part, we ask that you tell the researcher.

What Are the Risks of the Study?

Participation in a study may involve stress and inconvenience and loss of privacy. Some of the questions asked by the interviewer may make you feel uncomfortable. If this happens you can talk to the interviewers about it and you can choose not to answer any question that you do not want to. Despite our best efforts to preserve your confidentiality, information you provide may be associated with you. Such information could potentially embarrass you or affect your reputation in the event of a breach of confidentiality.

Are There Benefits to Taking Part in the Study?

You will not benefit directly from participating in this study, other than having the opportunity to express your opinions. You and others may benefit from the answers you provide because we will use this information to create a program that we hope will improve healthcare for Native American elders.

What About Confidentiality?

Efforts will be made to keep the personal information in your research record private and confidential. However, we cannot guarantee total privacy. Your personal information may be shared with others if required by applicable law or regulation, such as to report suspected child or elder abuse or neglect. Representatives from the Southwest Tribal Institutional Review Board that oversees research with human subjects may be permitted access to your records. However, your name will not be used in any published reports about this study.

What Are the Costs?

There are no costs to you for participating in this study.

You will be paid \$25 for participating in this interview.

What Are My Rights as a Participant?

Taking part in this study is voluntary. You do not have to answer questions that make you feel uncomfortable, or that you do not wish to answer. You may choose not to take part and you may choose to leave the study at any time. No one but the researcher will know if you decide not to participate. Nothing bad will happen to you if you decide not to participate.

Whom Do I Call if I Have Questions or Problems?

If you have any questions about the study, contact the Principal Investigator, Dr. Cathleen Willging at (505) 765-2328 or by email at CWillging@pire.org. You may also call the study coordinator, Patti Hokanson, at (505) 765-2325 or email her at PHokanson@pire.org.

If you have questions about your rights as a research participant you may call Rachell Tenorio, Southwest Tribal IRB Coordinator at (505) 764-0036. The IRB is a group of people who provide independent oversight of safety and ethical issues related to research involving human participants. For more information, you may also access their website at http://www.mynarch.net/SW_Tribal_IRB.aspx.

You will receive a copy of this form.

You can get a full copy of the study plan (research protocol) by asking the person interviewing you.

Signatures:

I agree to take part in this study.

I agree to allow this interview to be audio-recorded.
 I do not agree to allow this interview to be audio-recorded.

Printed Name of the Participant _____

Signature of the Participant _____

Date _____

Printed Name of the Person Obtaining Informed Consent_____

Signature of the Person Obtaining Informed Consent _____

Date _____



“Seasons of Care” Informed Consent Form

Public Administrators and Tribal Leaders

Study Title: Seasons of Care: Improving Native American Elder Access to and Use of Healthcare through Effective Health System Navigation

Purpose:

Dr. Cathleen Willging, a Senior Research Scientist at the Pacific Institute for Research and Evaluation (PIRE), is undertaking a research study that is funded by the National Institute on Minority Health and Health Disparities. This study has been reviewed and approved by the Southwest Tribal Institutional Review Board (IRB).

This is a research study to understand how to improve health insurance and health care for Native American elders (age 55+). Please take your time to make your decision about participating.

You are being invited to take part in this study because you participate in state and tribal efforts to provide health insurance and/or health care to Native American elders.

Why is This Study Being Done?

This research is being done because Native American elders often suffer from poor health and have a hard time getting good health care and paying for health care.

The purposes of this study are to:

- Understand how Native American elders use health insurance and health care.
- Understand the reasons that Native American elders have a hard time getting health insurance or health care.
- Train patient navigators who will help Native American elders learn about and use health insurance and health care.

How Many People Will Take Part in the Study?

About 144 people will take part in this study.

What is Involved in the Study?

- This study includes a **survey** about:
 - Your demographic information
 - Your work experience
 - Your experience with health reforms, including the Patient Protection and Affordable Care Act (ACA).

- This study includes **an interview** about:
 - State and tribal efforts to improve health insurance and health care for Native American elders
 - Your role in state and tribal efforts to improve health insurance and health care for Native American elders
 - Your opinions about other factors that affect the health of Native American elders.

Procedures:

- In this study, you will be asked to take part in a survey and interview with a member of our research team. You will be asked questions about your experience with health insurance and health care for Native American elders.
- The survey and interview will take about an hour. We will do the interview in a place where you feel safe and comfortable.
- The interview will be audio-recorded in order to make sure that all the information you provide is correctly written. You can refuse to answer any question at any time. You may ask to have the tape recorder turned off at any time. You will not be identified by name during the interview or on any paper or audio-recording in the study. All information gathered during the interview will be written on a paper using a code and not your name.
- The information you provide will be entered into a computer that is protected with a password. The information and audio-recordings will be stored in a locked cabinet behind a locked door, but your name will not be linked in any way to this information. The audio-recordings will be destroyed when this study is finished.
- We may contact you at a later date to participate in a separate activity related to the study.

How Long Will I Be in the Study?

We would like to interview you once, but we may contact you at a later date to participate in a separate activity related to the study. You can decide to stop taking part in the study at any time. If you decide to stop taking part, we ask that you tell the researcher.

What Are the Risks of the Study?

Participation in a study may involve stress and inconvenience and loss of privacy. Some of the questions asked by the interviewer may make you feel uncomfortable. If this happens you can talk to the interviewers about it and you can choose not to answer any question that you do not want to. Despite our best efforts to preserve your confidentiality, information you provide may be associated with you. Such information could potentially embarrass you or affect your reputation in the event of a breach of confidentiality.

Are There Benefits to Taking Part in the Study?

You will not benefit directly from participating in this study, other than having the opportunity to express your opinions. You and others may benefit from the answers you provide because we will use this information to create a program that we hope will improve healthcare for Native American elders.

What About Confidentiality?

Efforts will be made to keep the personal information in your research record private and confidential. However, we cannot guarantee total privacy. Your personal information may be shared with others if required by applicable law or regulation, such as to report suspected child or elder abuse or neglect. Representatives from the Southwest Tribal Institutional Review Board that oversees research with human subjects may be permitted access to your records. However, your name will not be used in any published reports about this study.

What Are the Costs?

There are no costs to you for participating in this study.

You will be paid \$25 for participating in this interview.

What Are My Rights as a Participant?

Taking part in this study is voluntary. You do not have to answer questions that make you feel uncomfortable, or that you do not wish to answer. You may choose not to take part and you may choose to leave the study at any time. No one but the researcher will know if you decide not to participate. Nothing bad will happen to you if you decide not to participate.

Whom Do I Call if I Have Questions or Problems?

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You will receive a copy of this form.

You can get a full copy of the study plan (research protocol) by asking the person interviewing you.

Signatures:

I agree to take part in this study.

I agree to allow this interview to be audio-recorded.
 I do not agree to allow this interview to be audio-recorded.

Printed Name of the Participant _____

Signature of the Participant _____

Date _____

Printed Name of the Person Obtaining Informed Consent_____

Signature of the Person Obtaining Informed Consent _____

Date _____



“Seasons of Care” Informed Consent Form Concept-Mapping Interview (Elders and Other Stakeholders)

Study Title: Seasons of Care: Improving Native American Elder Access to and Use of Healthcare through Effective Health System Navigation

Purpose:

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This is a research study to understand how to improve health insurance and health care for Native American elders (age 55+). Please take your time to make your decision about participating.

You are being invited to take part in this study because you are a Native American elder who uses health insurance and health care.

Why is This Study Being Done?

This research is being done because Native American elders often suffer from poor health and have a hard time getting good health care and paying for health care.

The purposes of this study are to:

- Understand how Native American elders use health insurance and health care.
- Understand the reasons that Native American elders have a hard time getting health insurance or health care.
- Train patient navigators who will help Native American elders learn about and use health insurance and health care.

How Many People Will Take Part in the Study?

About 144 people will take part in the whole study.

What is being asked of me?

- In this study, you will be asked to take part in an activity called concept-mapping. In this activity, you will be asked to look at cards with statements of about healthcare and health insurance for Native American elders written on them. We will ask you sort these statements into different piles and rank them
- The activity will take about 45 to 60 minutes.

- You can refuse to do the activity at any time. You will not be identified by name during the activity or on any paper or audio-recording in the study. All information gathered during the activity will be written on a paper using a code and not your name.
- The information you provide will be entered into a computer that is protected with a password. The information will be stored in a locked cabinet behind a locked door, but your name will not be linked in any way to this information.

How Long Will I Be in the Study?

We would like to invite you to do this activity once. You can decide to stop taking part in the study at any time. If you decide to stop taking part, we ask that you tell the researcher.

What Are the Risks of the Study?

Taking part in this study may involve stress, inconvenience, and loss of privacy. Some of the questions asked by the interviewer may make you feel uncomfortable. If this happens you can talk to the interviewers about it and you can choose not to answer any question that you do not want to. Despite our best efforts to preserve your confidentiality, information you give us may be associated with you. Such information could potentially embarrass you or affect your reputation in the event of a breach of confidentiality.

Are There Benefits to Taking Part in the Study?

There is no direct benefit to you for taking part in this study.

If you wish, you will receive a fact sheet with information about health insurance and health care options for Native American elders and phone numbers of individuals who can answer any questions you have about your health insurance and health care. In addition to having an opportunity to express your opinions, you and others may benefit from the answers you provide because we will use this information to create a program that we hope will improve healthcare for Native American elders.

What About Confidentiality?

Efforts will be made to keep the personal information in your research record private and confidential. However, we cannot guarantee total privacy. Your personal information may be shared with others if required by applicable law or regulation, such as to report suspected child or elder abuse or neglect. Representatives from the Southwest Tribal Institutional Review Board that oversees research with human subjects may be permitted access to your records. However, your name will not be used in any published reports about this study.

What Are the Costs?

There are no costs to you for participating in this study.

You will be paid \$25 for participating in this activity.

What Are My Rights as a Participant?

You may choose not to take part and you may choose to leave the study at any time. You do not have to answer questions that make you feel uncomfortable, or that you do not wish to answer. No one but the research team will know if you decide not to participate. Nothing bad will happen to you if you decide not to participate.

Whom Do I Call if I Have Questions or Problems?

If you have any questions about the study, contact the Principal Investigator, Dr. Cathleen Willging at (505) 765-2328 or by email at CWillging@pire.org. You may also call the study coordinator, Patti Hokanson, at (505) 765-2325 or email her at PHokanson@pire.org.

If you have questions about your rights as a research participant you may call Rachell Tenorio, Southwest Tribal IRB Coordinator at (505) 764-0036. The IRB is a group of people who provide independent oversight of safety and ethical issues related to research involving human participants. For more information, you may also access their website at http://www.mynarch.net/SW_Tribal_IRB.aspx.

You will receive a copy of this form.

You can get a full copy of the study plan (research protocol) by asking the person interviewing you.

Signatures:

I agree to take part in this study.

Printed Name of the Participant _____

Signature of the Participant _____

Date _____

Printed Name of the Person Obtaining Informed Consent _____

Signature of the Person Obtaining Informed Consent _____

Date _____