

## ***Summary of the Capstone Research Project by Jane Snake***

*NOTE 1: the content of this Summary is identical to the content of the Application to the IRB.*

*NOTE 2: "Jane Snake" is the student's real name. Not co-incidentally, "Jane Snake" is also the name of the principal modern-day character in the play Manahatta by Mary Kathryn Nagle.*

### **CAPSTONE RESEARCH TITLE:**

**Attitudes by RealName People with Diabetes  
Toward Diabetic Programs Offered by the RealName Tribal Health Clinic**

### **PRINCIPAL INVESTIGATOR:**

**Jane Snake, Fourth-year Undergraduate Student  
Tribal Governance and Business Management Baccalaureate Degree Program  
RealName Tribal College**

### **SHORT RESEARCH TITLE:**

**RealName Patient Satisfaction Research Survey on Diabetes**

### **Background Information:**

My Capstone Project for the Tribal Governance and Business Management (TGBM) 4-year Degree Program is a combination Patient Satisfaction Survey + Research Project conducted among people with diabetes of the RealName Tribe. Most, but not all, RealName people with diabetes are patients of the RealName Tribal Health Clinic. Type 2 Diabetes Mellitus is the most common chronic disease in the RealName Tribe, even more common the hypertension. The latest statistics are that fully 41% of the adult patients age 20+ of the Clinic have diabetes, as do 12% of patients age 11-19. I was a Community Health Representative (CHR) for eleven years before going back to RealName Tribal College to complete my A.A. degree and now to get a B.A. As a CHR, I personally saw the how devastating diabetes is in our people. I also have diabetes in my own family, and therefore I am at risk to develop it. Management of Tribal Health Clinics and Hospitals is studied in our TGBM Program.

I asked the Doctor Mary Jones, DO, Medex John Nez, PA-C, and Nurse Carl Billy, RN -- Medical Director, Executive Director, and Community Health Nurse of the RealName Tribal Health Clinic respectively -- if a survey of attitudes by people with diabetes toward the several programs the Clinic has for people with diabetes would be useful for the Clinic. All three enthusiastically said yes. I then asked first the RealName Health Board and then the RealName Tribal Council and for their approval of the Project; both organizations gave their approval. I then asked each organization to name people to the project's "Community Action/accountability Board (CAB)" to help with the Survey. The Members of the CAB named are:

- Dr. Jones, Clinic;
- Medex Nez, Clinic;
- Nurse Billy, Clinic;
- Mike Gladstone, my Academic Adviser;
- Mary Frank, Chair of the RealName Health Board; and
- four RealName people with diabetes chosen by the Health Board –
  - Elder woman with diabetes, Debbi Rasmus,
  - Elder man with diabetes, Billy Frank,
  - young woman with diabetes, Sarah Nez, and
  - young man with diabetes, Roger Bob).

The CAB helped develop the questions in the Survey so that the results of the Survey will be most helpful to the Clinic, Tribe, and people with diabetes. In the future, the CAB will help analyze the data the project obtains, and will help co-author the report of this research that I present to the RealName Tribal College, the RealName Health Board, and the RealName Tribal Council. These future actions of the CAB help the project follow the principles of “Community-Based Participatory Research (CBPR)” and “Tribally Engaged and Controlled Research (TECR),” and also help maximize conventional scientific and tribal/cultural rigor of the project.

**Purpose:**

The research is a Survey of attitudes toward the five programs that the Medical Clinic has for people with diabetes to help them control their diabetes better.

**Procedure:**

The Survey Packet consists of:

- The short Instruction page;
- The Information Sheet – the “Consent Form” without need for the person’s signature; and
- The three (3) page Survey Form itself --

together in unsealed 8½ by 12 inch envelopes called Survey Packets.

These Survey Packets will be in three sets of two large boxes: one in the waiting room for the RealName Medical Clinic; a second set in the waiting room for the RealName Dental Clinic; and the third in the waiting room for the RealName Pharmacy. Each set will be under a large sign announcing the research and inviting people to take a packet, read it, and to take the Survey if they agree to do so.

The short Instruction page asks the potential participant to read the Information Sheet / Consent Form carefully. It is OK if the person would like to take the packet home or elsewhere to discuss with someone, or to contact me to ask me questions.

The Information Sheet / Consent Form explains the Survey and also gives all information for a proper Consent Form. If the person wants to take the Survey after reading the Sheet / Form, that person then:

1. answers the Survey, then
2. places the Survey back in the Envelope (but keeps the Instructions page and Information Sheet / Consent Form); then
3. seals the envelope with the Survey; then
4. places the envelope through the slot into the Survey Collection Box, attached to the large box with the unused Survey Packets.

I estimate that the entire process to read, answer, and complete the Survey will take 15 minutes.

The RealName IRB staff helped me draft the Information Sheet / Consent Form to contain all necessary information, yet also have the best readability level to be most easily understandable, and to be most concise (and thus in fact to be more frequently read in its entirety) as possible. The Information Sheet / Consent Form, attached, is only 312 words, and has a readability level of 6.4<sup>th</sup> grade (the usual level of a short popular magazine article) – yet I believe has everything required by 45 CFR 46.

I cannot be in the RealName Clinic when participants will fill out the Survey because I am a full-time student at RealName Tribal College. I thus cannot personally obtain informed consent with participants. I will talk directly with a potential participant generally only if/when the person contacts me with a question. I have discussed the Survey at the Tribal-wide General Council meeting, and will do so whenever I have a chance anywhere else. The RealName Tribal newspaper has agreed to announce and describe my survey for free. I will also have many packets and be present at an Information Table in the early-spring Pow-Wow, to discuss the Survey with anyone interested.

I consulted with the leaders of the Clinic (see above), my Academic Advisor, and staff of the RealName IRB to develop this procedure. We want to reach as many people as we can to take the Survey, without being limited by the very short times I would be able to directly talk with individuals to recruit them, and without burdening any RealName Clinic staff. This procedure allows anyone to take the survey, whether or not they are patients at the Clinic. *This procedure is identical to the usual procedure for patient satisfaction surveys at the Clinic. Both patients and Clinic staff are used to this procedure.*

Some RealName people with diabetes get their care elsewhere and are not full patients in the Medical Clinic. Many of those fill their medicine at the RealName Pharmacy located in the Clinic. Some “non-patients” nevertheless participate in one or more programs for people with diabetes or family members of people with diabetes. My Project hopes that many of those people answer the Survey.

### **Format of the Survey and Questions:**

The Survey will be anonymous. For the demographic questions, it will ask only:

- Is the person at least 18 years of age or older? *[If not, please do not answer the survey.]*
- Is the person a member of the RealName Tribe? (Yes / No)
- Does the person have diabetes? (Yes / No)
- Is the person a patient of the RealName Tribal Health Center? (Yes / No)
- Is the person a woman or a man? (Woman / Man)

The survey lists separately each of the five programs the Clinic has to help treat and/or prevent diabetes. For each program listed, the survey asks the same set of questions:

- the respondent’s attitude about the program, using a Likert Scale format;
- if the respondent had participated in the program (Yes / No);
- what the respondent thought was best about the program (open-ended question); and
- the respondent’s suggestions for improvements the program could make.

At the end of the Survey, the final single question asks what additional, new, programs for people with diabetes do they suggest.

### **Confidentiality and Privacy:**

The survey collects no identifiers other than broad demographic variables: gender (woman or man), age 18+ (yes / no), RealName Tribal member (yes / no), and patient of Clinic (yes / no). No demographic variable, either by itself or in combination with any other variable or even all variables, will enable “statistical identification.” I therefore am confident that this Survey is totally anonymous.

### **Request to IRB to waive “documentation of consent”:**

I discussed this Survey with the staff of the RealName IRB from the beginning. This Survey and the way it is conducted are the same as the patient satisfaction surveys the Clinic does twice a year. (The only differences are that this Survey is about *only* the Clinic’s diabetes programs, and has more detailed questions about only one topic, and that I will conduct more detailed quantitative and qualitative analyses of the results.) I thoroughly appreciate the IRB staff’s help and advice. They advised me to request that the IRB waive “Document of Consent” for the following reasons:

- this Survey is of adults only;
- it is totally anonymous;
- it does not ask for sensitive information; and
- patient satisfaction surveys do not normally require signed consent forms.

These four aspects together meet the requirements for the IRB to waive “documentation of consent” – that is, to not require that I ask everyone to sign a Consent Form. I thus request that the IRB waive “documentation of consent.”

### **Future plan for Analysis and Dissemination:**

I will partner with the Community Action/accountability Board (CAB) to analyze, interpret, and disseminate results of the survey to the Clinic, Health Board, Tribal Council, and Tribe. I will also report this research to the RealName TCU, during the 2-day reporting by all students of their Capstone Project in the Tribal Governance and Business Degree Program, shortly before spring graduation with a BA degree.

After I am finished with the analyses and reports needed to achieve the Purpose of this research project, I will give all data and materials to the RealName Tribe for its ownership and control of future uses of the de-identified data and materials. I will first de-identify the Survey Forms by typing a copy of every Form, so that no-one can identify who answered a given Survey Form by any distinctive handwriting on the Survey.

I will also ask the RealName Tribal Council if it would give permission for the Mathematics Dept. of the RealName Tribal College to retain a copy of the same dataset for students taking statistics courses in the future. The sole permitted use of the dataset would be for the students to apply their statistical knowledge to a real-life dataset about a topic of special interest to the many students who have diabetes in their family. If given permission by the Tribe, the College will sign a legal agreement with the Tribe that the dataset will not be given to anyone else and not used for any other reason.

## **INSTRUCTIONS for PATIENT SATISFACTION RESEARCH SURVEY**

### **RealName Patient Satisfaction Research Survey on Diabetes**

**By researcher Jane Snake, Fourth-year Undergraduate Student  
Tribal Governance and Business Management Baccalaureate Degree Program  
RealName Tribal College**

*(These Instructions are taped to the outside of every the unsealed 9 inch by 12 inch unsealed envelope that contains two copies of the Information Sheet / Consent Form and one copy of the Survey. These Instructions are also taped to each side of the box holding those envelopes. These Instructions are also considered to Recruitment documents.)*

I am Jane Snake, former CHR in the RealName Tribal Health Clinic. My parents are (*Mon's Name*) and (*Dad's Name*). I am doing a research project to help Clinic the find out what patients with diabetes think about the Clinic's programs to help people prevent diabetes, and to help people with diabetes stay healthy.

The research project is a patient satisfaction survey about the diabetes programs the Clinic has. I am doing the survey also as part of my Capstone Project before I graduate this June from the RealName Tribal College.

I invite you to learn more about the patient satisfaction survey, to see if you would like to take part in it. The survey is explained in each large envelope in this box *that is not sealed*. ***If you see a sealed envelope in this box, please put it in the box next to this one marked "Please put Answered Surveys in this box."*** Each envelope has two Information Sheets / Consent Form, plus one survey. The survey is for people age 18 or older. You might be interested in taking part, please read what is in an envelope to learn more about the survey.

***If you want to take the survey*** after you read the Information Sheet / Consent Form about it, please do these steps. (You may also the survey itself, if you want.)

1. Please keep a copy of the Information Sheet / Consent Form. It is has info that you can use in the future. For instance, it tells you how to get in touch with me if you want to so. You can keep the other copy of the Info Sheet as well, if you want.
2. Please Fill out and answer the survey. You are free to not answer any question you do not want to.
3. Please put your survey with your answers back in the envelope.
4. Please seal the envelope closed.
5. Please put your sealed envelope in the box next to this one marked ***"Please put Answered Surveys in this box,"*** through the slot at the top of the box.

Hy'shqe Siam!

## **INFORMATION SHEET / CONSENT FORM**

### **RealName Patient Satisfaction Research Survey on Diabetes**

**By Jane Snake, Fourth-year Undergraduate Student  
Tribal Governance and Business Management Baccalaureate Degree Program  
RealName Tribal College**

**The RealName Tribal Health Clinic and Jane Snake ask you to take part in a patient satisfaction research survey about programs for patients with diabetes.**

The Clinic wants to know what is best about its programs, what could be improved, and what new programs are needed. The Clinic hopes to use the Survey results to plan for better care for all of us.

We ask all patients with diabetes age 18 years or older to take the Survey.

We know of no risks or harms to you to taking part. The survey is anonymous. No-one can know who filled out a Survey form, because no names are on it. It takes about 15 minutes to finish.

You will not receive any benefit right now by taking part. The RealName Tribe may benefit if most patients answer the survey and give their ideas! We hope you benefit in the future due to the Clinic improving its programs and starting new programs that are needed.

Results of the Survey will be given to the entire RealName Tribe.

#### **Taking part is voluntary.**

If you do not take part, you will have no penalty and will lose no service by the Clinic or others. You may leave any question blank, but we hope you will answer as many questions as you can.

If you have **questions about the survey**, please contact **Jane Snake**, phone \_\_\_-\_\_\_-\_\_\_\_ or at the RealName Tribal College, or by email (JSnake@RNTC.edu). If you have a **complaint, grievance, or other concern**, please contact **Ed Ethics**, Chair, RealName IRB. Call him at \_\_\_-\_\_\_-\_\_\_\_ or visit him at the Tribal Office.

#### **Please leave the survey form in the boxes by medical records, dental, or pharmacy.**

Please take this Information Sheet / Consent Form with you. Medical records also has copies of the Sheet and Survey.

**Thank you for helping to build a healthier world for the RealName Tribe!**

**SURVEY for RESEARCH PROJECT:**

**Attitudes by RealName People with Diabetes  
Toward Diabetic Programs Offered by the RealName Tribal Health Clinic**

**By researcher Jane Snake, Fourth-year Undergraduate Student  
Tribal Governance and Business Management Baccalaureate Degree Program  
RealName Tribal College**

**1. Please answer these brief questions about you.**

- a. Are you at 18 years of age or older? Yes\_\_\_ NO\_\_\_  
*If "NO, " please do not go further. Please do not answer the Survey.*
- b. Are you a member of the RealName Tribe? Yes\_\_\_ No\_\_\_
- c. Do you have diabetes? Yes\_\_\_ No\_\_\_
- d. Are you a patient of the RealName Tribal Health Center? Yes\_\_\_ No\_\_\_
- e. What is your gender? Woman\_\_\_ Man\_\_\_

**(A) Name of Program: Program ".....A....."**

**Attitude or feelings toward the Program:** *Please write an "X" where on the line your feelings are.*

\_\_\_\_\_  
**Strongly Unfavorable    Mildly Unfavorable    Neutral    Mildly Favorable    Strongly Favorable    NO Feeling or NO Knowledge of Program**

**Have you every participated in the Program?** Yes\_\_\_ No\_\_\_

**What do you think is best about the Program?** \_\_\_\_\_

**Please write your suggestions to improve the Program:** \_\_\_\_\_

**(B) Name of Program: Program ".....B....."**

**Attitude or feelings toward the Program:** *Please write an "X" where on the line your feelings are.*

\_\_\_\_\_  
**Strongly Unfavorable    Mildly Unfavorable    Neutral    Mildly Favorable    Strongly Favorable    NO Feeling or NO Knowledge of Program**

**Have you every participated in the Program?** Yes\_\_\_ No\_\_\_

**What do you think is best about the Program?** \_\_\_\_\_

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Please write your suggestions to improve the Program: \_\_\_\_\_

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(C) Name of Program: Program ".....C....."

Attitude or feelings toward the Program: *Please write an "X" where on the line your feelings are.*

_____	_____	_____	_____	_____	_____
Strongly	Mildly	Neutral	Mildly	Strongly	NO Feeling or
Unfavorable	Unfavorable		Favorable	Favorable	NO Knowledge of Program

Have you every participated in the Program? Yes\_\_\_ No\_\_

What do you think is best about the Program? \_\_\_\_\_

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Please write your suggestions to improve the Program: \_\_\_\_\_

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(D) Name of Program: Program ".....D....."

Attitude or feelings toward the Program: *Please write an "X" where on the line your feelings are.*

_____	_____	_____	_____	_____	_____
Strongly	Mildly	Neutral	Mildly	Strongly	NO Feeling or
Unfavorable	Unfavorable		Favorable	Favorable	NO Knowledge of Program

Have you every participated in the Program? Yes\_\_\_ No\_\_

What do you think is best about the Program? \_\_\_\_\_

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Please write your suggestions to improve the Program: \_\_\_\_\_

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(E) Name of Program: Program “.....E.....”

Attitude or feelings toward the Program: Please write an “X” where on the line your feelings are.

Strongly      Mildly      Neutral      Mildly      Strongly      NO Feeling or  
Unfavorable   Unfavorable    Favorable      Favorable      NO Knowledge of Program

Have you every participated in the Program?    Yes\_\_\_ No\_\_

What do you think is best about the Program? \_\_\_\_\_

Please write your suggestions to improve the Program: \_\_\_\_\_

**FINAL QUESTION: What new or additional program, to help people prevent diabetes or to help people with diabetes stay healthy, do you suggest that the Clinic start?**

Why? \_\_\_\_\_

**Please:**

- put your Survey back into the large envelope, then
- seal the envelope, then
- insert the sealed envelope with your Survey through the slot at the top of the next box.

**Please take the Information Sheet / Consent Form with you.**

**THANK YOU!**

**Jane Snake and the RealName Tribal Health Clinic.**