Using REDCap (Research Electronic Data CAPture) to promote healthy behaviors in diverse Utah women

The Coalition for a Healthier Community for Utah Women and Girls (UWAG)
Presentation Overview

• Introduction to Project and Partners
• Introduction REDCap
• Use of REDCap in the UWAG Study
• Panel Discussion with UWAG Team
Utah Women’s Health Coalition
UWAG Partners

• Community Faces of Utah
  • Best of Africa
  • Calvary Baptist Church
  • Hispanic Health Care Task Force
  • Urban Indian Center
  • National Tongan American Society
  • University of Utah (C/E Team of the CCTS)
  • Utah Department of Health

• University of Utah (COEWH and UWHC)
Our Strategy

• Community Based Participatory Research
  • Collaborative approach
  • Input and feedback from all partners about all aspects of study
  • Flexibility in protocols so each community can tailor activities
  • Bi-directional/multi-directional learning

• 2 Phases: Needs Assessment & Intervention/Evaluation

• Focus on sustainability & capacity building
What is the UWAG Study?

• Community Wellness Coaching Program
  • Motivational interviewing
  • Individualized goal setting
  • Practical strategies for healthy eating and active living
  • Based on CDC’s A New Leaf program
    • Tailored using CBPR approach by UWAG partners
    • Monthly activities developed by each CFU community

• Coaches recruited by each CFU community, trained by UWAG staff
  • English, Spanish, Kirundi-speaking
Study Design

• Randomized trial of 12 month coaching program
  • Monthly contact vs. quarterly contact with coach

• Is a COMMUNITY WELLNESS COACHING approach more effective in decreasing obesity risk factors when administered with monthly (high intensity) vs. 4 times per year (low intensity) contacts?

• If so, does the improvement in health outcomes warrant the additional costs?
Implementation

• REDCap database developed
• CFU community leaders recruited community members to serve as coaches
• Coaches trained by UWAG staff
  • HIPAA, CITI
  • Wellness coaching
  • Data collection: interview and clinical measures
  • REDCap
What is REDCap?

- **Research Electronic Data Capture**
  - Developed by Vanderbilt University

- mySQL, Apache, php, javascript

- HIPAA **compliant** capable

- Web interface - must have internet connection!
How has REDCap been used?

- The **REDCap Consortium** is composed of **1,416 active institutional partners** in **90 countries**
- The REDCap application allows users to build and manage online surveys and databases quickly and securely
- Currently in use by **164,000 projects** with over **224,000 users** spanning numerous research focus areas across the consortium
Use of REDCap in UWAG Study

• Wellness coach collects baseline & follow-up data for 12 months
  • Interview questions:
    • Health knowledge and behaviors
    • Perceived benefits and barriers
    • Social Support
    • Mental health
  • Clinical data:
    • Blood pressure, BMI, waist-to-hip ratio measured
  • Coaching, goal setting, tracking progress
Using REDCap to collect and store interview data:

**Body Image**

74. How happy are you with your current weight?
- **Response Options:**
  - Never
  - Usually
  - Sometimes
  - Always

**Depression Screening PHQ.2**

Next I would like to ask you some questions about your mood.

75. Over the past two weeks, how often have you been bothered by any of the following problems?

- Little interest or pleasure in doing things?

  - 0 - Not at all (ENTER 0 IN THE ANSWER)
  - 1 - Several days (ENTER 1 IN THE ANSWER)
  - 2 - More than half the days (ENTER 2 IN THE ANSWER)
  - 3 - Nearly every day (ENTER 3 IN THE ANSWER)

ENTER THE NUMBER FROM THE WOMAN'S ANSWER.

(IF PARTICIPANT DOES NOT KNOW OR IS RELUCTANT TO ANSWER ASK THEM FOR THEIR BEST GUESS)

* must provide value

76. Over the past two weeks, how often have you been bothered by any of the following problems?

- Feeling down, depressed or hopeless?

  - 0 - Not at all (ENTER 0 IN THE ANSWER)
  - 1 - Several days (ENTER 1 IN THE ANSWER)
  - 2 - More than half the days (ENTER 2 IN THE ANSWER)
  - 3 - Nearly every day (ENTER 3 IN THE ANSWER)

ENTER THE NUMBER FROM THE WOMAN'S ANSWER.

(IF PARTICIPANT DOES NOT KNOW OR IS RELUCTANT TO ANSWER ASK THEM FOR THEIR BEST GUESS)

* must provide value
13. Mu ibi birukira ni ibihye vyorekana iyo mukora?
(MAY SELECT MORE THAN ONE OPTION)
(READ RESPONSES)

14. Mukorera hanze yo mu rugo?
* must provide value

15. Umuryango wanye wakoreyamadolori angehe mu kwezi guheje (uzijemo amahera yo gutashana abana, imashanyo ya leta nk'amahora leta iha abadahise akazi, imashanyo y'iyokurya)?
* must provide value

16. Mu ndwi isanzwe, mukoresha amahera angehe mu kugura iyo kurya?
Murashiro amahera mu gura iy'okurya yo mu rugo, iyo kurya mu gura muburigo, Mushiro n'imashanyo y'iyokurya mwarona.
* must provide value

17. Ni nde akorema amahera mu muryangwa?
(DO NOT READ: If woman reports two or more equal breadwinners click “other” and enter the details.)
* must provide value

18. Mumafise astranse yo kwivuza aki astranse bishura mbeza ya HMO, canke astranse za leta nka Medicare canke Indian Health Service?
* must provide value

100. Trabaja tiempo completo para un empleador
101. Trabaja medio tiempo para un empleador
102. Tiene su propio empleo
103. Estudiante
104. Arma de casa
105. Esta activamente buscando trabajo
106. Desempleada
107. Otro
108. No sabe/no esta segura
109. Se rehuso a responder

14. Trabaja fuera de casa?
* must provide value

15. Cual fue su ingreso familiar el ultimo mes en $ dólares (incluyendo pension, manutencion, apoyo del gobierno tal como desempleo, seguro social y estampilas para comida)?
* must provide value

16. En una semana regular, aproximadamente cuanto dinero gasta en comida para su casa? Esto debe incluir el dinero que gasta en la despensa y en comida que compra de los restaurantes o lugares de comida rapida. Por favor incluya las estampilas para comida en este total si las recibe.
* must provide value

17. Quien es el sosten principal de la familia o el que gana el sueldo en su casa?
(Si la mujer reporta dos o mas personas que sostienen a la familia haga clic en “otro” e ingrese los detalles.)
* must provide value

18. Tiene algun tipo de cobertura medica, incluyendo seguro medico, planes propuestos tales como HMOs o planes del gobierno tales como Medicare o Servicio Medico Indigena?
* must provide value
Clinical data:

**Event Name:** Baseline (Arm 1: Baseline)

<table>
<thead>
<tr>
<th>Event Description</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Date clinical measures taken</td>
<td>12-07-2012</td>
</tr>
<tr>
<td>1a. Time the clinical measures started</td>
<td>17:51</td>
</tr>
<tr>
<td>2. Systolic Blood Pressure (1st Measurement)</td>
<td>131</td>
</tr>
<tr>
<td>3. Diastolic Blood Pressure (1st Measurement)</td>
<td>82</td>
</tr>
<tr>
<td>4. Systolic Blood Pressure (2nd Measurement)</td>
<td>125</td>
</tr>
<tr>
<td>5. Diastolic Blood Pressure (2nd Measurement)</td>
<td>87</td>
</tr>
<tr>
<td>6. Systolic Blood Pressure (3rd Measurement)</td>
<td>130</td>
</tr>
<tr>
<td>7. Diastolic Blood Pressure (3rd Measurement)</td>
<td>86</td>
</tr>
<tr>
<td>8. Average Systolic Blood Pressure</td>
<td>128.7</td>
</tr>
<tr>
<td>9. Average Diastolic Blood Pressure</td>
<td>84.7</td>
</tr>
</tbody>
</table>

PLEASE SCROLL DOWN AND HIT "SAVE AND CONTINUE."

10. Height in inches | 64 |
11. Weight in pounds | 150 |
12. Body Mass Index | 25.7 |
13. Is the woman pregnant? | No |
13a. Waist Circumference in Inches | 30 |
Personalized Coaching Prompts

DEPRESSION SCREENING PHQ-2

Next I would like to ask you some questions about your mood.

75). Over the past two weeks, how often have you been bothered by any of the following problems?

Little interest or pleasure in doing things?
0 = Not at all (ENTER 0 IN THE ANSWER)
1 = Several days (ENTER 1 IN THE ANSWER)
2 = More than half the days (ENTER 2 IN THE ANSWER)
3 = Nearly every day (ENTER 3 IN THE ANSWER)

ENTER THE NUMBER FROM THE WOMAN'S ANSWER.

(IF PARTICIPANT DOES NOT KNOW OR IS RELUCTANT TO ANSWER ASK THEM FOR THEIR BEST GUESS)
* must provide value

75). Over the past two weeks, how often have you been bothered by any of the following problems?

Feeling down, depressed or hopeless?
0 = Not at all (ENTER 0 IN THE ANSWER)
1 = Several days (ENTER 1 IN THE ANSWER)
2 = More than half the days (ENTER 2 IN THE ANSWER)
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ENTER THE NUMBER FROM THE WOMAN'S ANSWER.

(IF PARTICIPANT DOES NOT KNOW OR IS RELUCTANT TO ANSWER ASK THEM FOR THEIR BEST GUESS)
* must provide value

SLEEP

Let's talk briefly about how much sleep you get. You reported that on average, you get:

26). Less than 7 hours of sleep per night. Adults need 7-9 hours of sleep per night, and based on what you told me, you are not getting enough sleep each night. Sleeping 7-9 hours per night can actually help with many health problems including heart disease, diabetes, depression, and obesity.

DEPRESSION

Finally, during the interview, I asked you a series of questions to evaluate your mental health. Your answers to these questions are added together to give score which tells me whether you may be suffering from depression or not.

27). Your score on the depression screening questions indicates that you may be suffering from depression. I recommend that you make an appointment with a health care provider for a mental health evaluation. I can help you find a health care provider for this if you'd like.
### Goal Setting Tools

<table>
<thead>
<tr>
<th>Question</th>
<th>Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>30a. What area of nutrition do you want to focus on?</td>
<td></td>
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<tr>
<td>27a. How many total servings of fruits AND vegetables do you want to eat?</td>
<td>3</td>
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<td>* must provide value</td>
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<td>30b. When will you do this?</td>
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<td>* must provide value</td>
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<td>30c. How long do you plan to work on this goal?</td>
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<tr>
<td>(PLEASE ENTER A SUMMARY OF THE &quot;WHAT,&quot; &quot;WHEN,&quot; AND &quot;FOR HOW LONG.&quot; )</td>
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<td>* must provide value</td>
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<tr>
<td>30d. So based on the answers to these questions, your nutrition goal is:</td>
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<tr>
<td>(PLEASE ENTER A SUMMARY OF THE &quot;WHAT,&quot; &quot;WHEN,&quot; AND &quot;FOR HOW LONG.&quot; )</td>
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<td>30d). On a scale of 0-10, where &quot;0&quot; means not important and &quot;10&quot; means extremely important,</td>
<td>6</td>
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<td>about how important is this goal to you?</td>
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<td>30e). On a scale from 0-10, where &quot;0&quot; means you are not confident and &quot;10&quot; means you are</td>
<td>6</td>
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<td>very confident, about how confident are you that you can reach this goal?</td>
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<td>* must provide value</td>
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<td>30g). Would you like to set another nutrition goal? It is okay to focus on one goal at a</td>
<td>No</td>
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<td>time, but if there is something else you would like to focus on, I can help you with another</td>
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<td>goal?</td>
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<td>* must provide value</td>
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</tbody>
</table>
Randomization

41.) WHICH COMMUNITY WELLNESS COACH COMPLETED THIS INTERVIEW?
(Please type your name)
* must provide value

42). Randomize

Form Status
Complete?
Incomplete
### Study ID 3002 Sara, Simonsens
(Arm 2: High Intensity)

<table>
<thead>
<tr>
<th>Data Collection Instrument</th>
<th>Month 1 (1)</th>
<th>Month 2 (2)</th>
<th>Month 3 (3)</th>
<th>Month 4 (4)</th>
<th>Month 5 (5)</th>
<th>Month 6 (6)</th>
<th>Month 7 (7)</th>
<th>Month 8 (8)</th>
<th>Month 9 (9)</th>
<th>Month 10 (10)</th>
<th>Month 11 (11)</th>
<th>Month 12 (12)</th>
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### Study ID 1006 Kassy, K
(Arm 3: Low Intensity)

<table>
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<th>Data Collection Instrument</th>
<th>Month 4 (1)</th>
<th>Month 8 (2)</th>
<th>Month 12 (3)</th>
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<tbody>
<tr>
<td>Participant Name</td>
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<td>Participant Contact Tracking</td>
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<td>Four Month Interview</td>
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<td>Twelve Month Interview</td>
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<td>UWAG Staff Review</td>
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</table>
The Calendar application can be used as a project calendar within this project to help organize your schedule and keep track of any upcoming events. It will allow you to add or modify calendar events and then view them either in a daily, weekly, or monthly format below. To add a new note or calendar event to any day, click + New at the top of that day’s box to begin entering the information. Since you have already defined multiple events for this project, you may additionally generate a schedule using your pre-defined Events, which will then be added to the calendar.

<table>
<thead>
<tr>
<th>Sunday</th>
<th>Monday</th>
<th>Tuesday</th>
<th>Wednesday</th>
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</table>

Note: The calendar includes events from different months and years, such as "Month 1", "Month 2", "Year 2 Follow-up", etc.
The projected schedule below was automatically generated for Study ID "2503" based on your pre-defined Events for Arm 2. You may change the value of any dates generated below simply by clicking inside the date box and selecting a new date. Any dates generated below that fall on weekends will be listed in **red**. Click the Create Schedule button to finalize this schedule, which will then be added to the Calendar.

<table>
<thead>
<tr>
<th>Time (optional)</th>
<th>Date / Day of Week</th>
<th>Event Name</th>
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<tbody>
<tr>
<td><strong>05/13/2016</strong></td>
<td>Wednesday</td>
<td>Month 1</td>
</tr>
<tr>
<td><strong>06/12/2016</strong></td>
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<td>Month 2</td>
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<td><strong>07/12/2015</strong></td>
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<td><strong>08/11/2015</strong></td>
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<td><strong>09/10/2015</strong></td>
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<td><strong>02/07/2016</strong></td>
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<td><strong>03/08/2016</strong></td>
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<tr>
<td><strong>04/07/2016</strong></td>
<td>Thursday</td>
<td>Month 12</td>
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<td><strong>04/02/2017</strong></td>
<td><strong>Sunday</strong></td>
<td>Year 2 Follow-up</td>
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<tr>
<td><strong>03/28/2018</strong></td>
<td><strong>Wednesday</strong></td>
<td>Year 3 Follow-up</td>
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<tr>
<td><strong>03/23/2019</strong></td>
<td><strong>Saturday</strong></td>
<td>Year 4 Follow-up</td>
</tr>
</tbody>
</table>

Create Schedule  Cancel
Storage of Supplemental Files

- Consent Documents
- Referral Forms
- Audio Files of Coaching and Interviews
Data Access

• Each community has access to their own data
  • Personalized reports
• Study staff have access to all data
• Easy export to SAS, STATA, SPSS
Conclusions

• REDCap is a great tool for CBPR work
• Low cost
• Community partners can access their own data
• Facilitates data collection/coaching by lay health workers
  • Multiple languages
  • Randomization
  • Scheduling and calendar
  • Tailored coaching prompts based on participant data
  • Personalized goal-setting
Thanks to:

• Community Faces of Utah
  - Best of Africa: Valentine Mukundente, Esperance Rugamwa
  - Calvary Baptist Church: Pastor France A. Davis, Doriena Lee, Patricia Otiede, Cathy Wolfsfeld
  - Hispanic Health Care Task Force: Sylvia Rickard, Dee Dee Labato, Ana Sanchez-Birkhead, Jorge Arce-Laretta, Jeannette Villalta, Natalie Gutierrezes, Olga Rubiana, Claudia Gonzalez
  - National Tongan American Society: Fahina Tavake-Pasi, Ivoni Nash, Edris Netzler Aiono, Se Toki
  - Urban Indian Center Ed Napia, Penelope Pinnecoose

• University of Utah
  - Kathleen Digre—Co-PI
  - Heather Coulter, Leanne Johnston
  - Patricia Eisenman
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  - Stephen Alder, Louisa Stark
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Extra Slides
Changes in Health Behaviors between Baseline and Follow-Up

Increased fruit/vegetable consumption
- Baseline to 4 Months: 57.6%
- Baseline to 8 Months: 62.1%
- Baseline to 12 Months: 67.8%

Increased physical activity
- Baseline to 4 Months: 46.7%
- Baseline to 8 Months: 50.0%
- Baseline to 12 Months: 64.4%
Changes in Weight between Baseline and Follow-Up

Lost 5% or more of baseline weight

- Baseline to 4 Months: 13%
- Baseline to 8 Months: 21%
- Baseline to 12 Months: 22%