

Health Informatics to Support the Underserved for Population Health and Precision Medicine

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ABSTRACT

Background

According to the literature, minorities are grossly underrepresented in research studies. This is deemed a multifaceted challenge and as such has not been a focus of attention in healthcare. However, with the advent of precision medicine, there is renewed interest in addressing this challenge.

Project or Case Description

The *All of Us* research program is one answer to this problem. A noteworthy part of the *All of Us* research program is its concerted effort to include populations that have traditionally been overlooked in health care research. Focus of this specific project was to recruit and educate healthcare providers such as physicians to support the *All of Us* research project and encourage their patients to enroll.

Purpose

The purpose of this report is to summarize how health informatics students supported a provider-based outreach effort for the *All of Us* Research Program.

Methodology for Proposed Intervention

The study design for this provide-based event was a pre- and post-intervention model. Hardcopy surveys were used to collect information from study participants before a lecture/discussion style presentation on the *All of Us* research program. Each data collection paper form was identified with a random case number [in the upper left corner of the form] and entered into an online data collection and management program called PsychData.com. The paper data collection forms were then entered into the PsychData.com online survey by the Texas Woman's University (TWU) team members, consisting of a TWU professor and two health informatics students. The data files were then exported to a statistical software analysis package for descriptive and comparative analysis by this same team.

Results

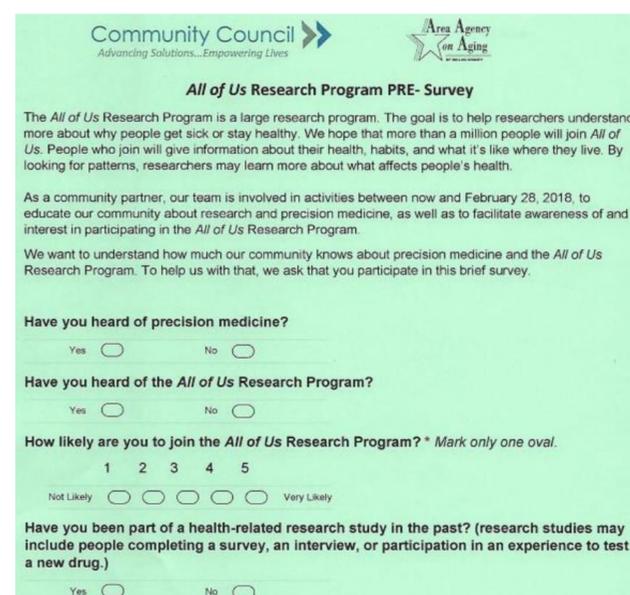
Results will be presented in two parts. First, an overview of the findings will be presented followed by a comparison of the pre- and post-intervention participant responses.

STUDY

Methodology

The study design for this outreach event was a pre- and post-intervention model. Hardcopy surveys were used to collect information from study participants before a lecture/discussion style presentation on the *All of Us* Research Program. The survey collected information about general awareness of precision medicine and about the likelihood that one would support participation in the National Institutes of Health (NIH) nationwide study. Data collection paper forms were provided to the participants to elicit this information. These paper forms were initially distributed by the Community Council staff upon arrival of participants and then collect when the participants were departing after the event. See Appendix A and B for the participant data collection paper forms used in the pre- and post-intervention data collection phases, respectively.

Pre-Survey via IBM SPSS



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All of Us Research Program PRE-Survey

The *All of Us* Research Program is a large research program. The goal is to help researchers understand more about why people get sick or stay healthy. We hope that more than a million people will join *All of Us*. People who join will give information about their health, habits, and what it's like where they live. By looking for patterns, researchers may learn more about what affects people's health.

As a community partner, our team is involved in activities between now and February 28, 2018, to educate our community about research and precision medicine, as well as to facilitate awareness of and interest in participating in the *All of Us* Research Program.

We want to understand how much our community knows about precision medicine and the *All of Us* Research Program. To help us with that, we ask that you participate in this brief survey.

Have you heard of precision medicine?
Yes No

Have you heard of the *All of Us* Research Program?
Yes No

How likely are you to join the *All of Us* Research Program? * Mark only one oval.
1 2 3 4 5
Not Likely Very Likely

Have you been part of a health-related research study in the past? (research studies may include people completing a survey, an interview, or participation in an experience to test a new drug.)
Yes No

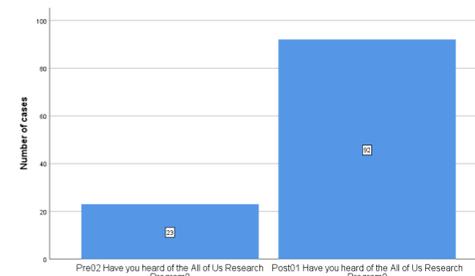
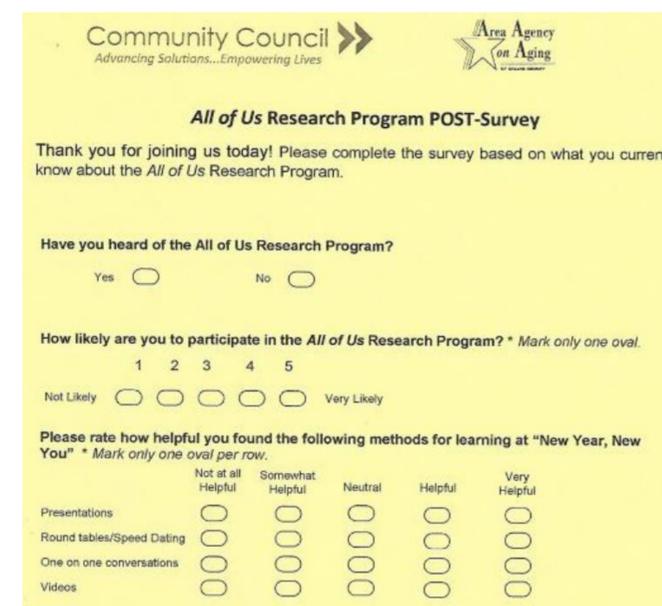


Figure 2. Comparison of the number of participants who indicated "Yes" to having heard of the *All of Us* Research Program. Statistically significant at the p .001 level.

Data Collection and Analysis

Color-coded data collection paper forms (see Appendix A through D) were used to collect anonymous response from participants. No participant identifying information was collected on these forms. These were initially distributed by the Community Council staff upon arrival of participants and then collect when the participants were departing after the event. The paper data collection forms were then entered by the TWU team members. The data from these forms were entered into an online survey database provided the TWU team members. The data files were then exported to a statistical software analysis package for descriptive and comparative analysis. Results will be presented in two parts. First, analysis of the community-oriented recruitment event will be provided. Secondly, analysis of the provider-oriented awareness event.

Post-Survey via IBM SPSS



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All of Us Research Program POST-Survey

Thank you for joining us today! Please complete the survey based on what you currently know about the *All of Us* Research Program.

Have you heard of the All of Us Research Program?
Yes No

How likely are you to participate in the *All of Us* Research Program? * Mark only one oval.
1 2 3 4 5
Not Likely Very Likely

Please rate how helpful you found the following methods for learning at "New Year, New You" * Mark only one oval per row.

	Not at all Helpful	Somewhat Helpful	Neutral	Helpful	Very Helpful
Presentations	<input type="radio"/>				
Round tables/Speed Dating	<input type="radio"/>				
One on one conversations	<input type="radio"/>				
Videos	<input type="radio"/>				

Table 3
How Helpful was the Educational Approach?

Descriptive Statistics			
	N	Mean	Std. Deviation
Post0301 Presentations	190	3.78	1.256
Post0302 Round tables/Speed Dating	168	3.68	1.390
Post0303 One on one conversations	173	3.77	1.300
Post0304 Videos	169	3.75	1.248

Table 3 indicates that all four approaches were helpful as suggested by mean [average] scores of 3.68 to 3.78 on a range of 1 not helpful to 5 very helpful.

Outcome

Results

Overall there was great attendance at the community-oriented event with over 250 in attendance and at least 220 completing surveys. See Table 1.

Table 1. Count of Pre and Post-Surveys

Pre or Post Survey Grp		
	Frequency	Percent
Pre	220	52.5
Post	199	47.5
Total	419	100.0

Data was also collected on how helpful the educational approaches were. The presentation approaches were: lecture presentation, round table/speed dating, one-on-one conversations, and videos. Table 3 indicates that all four approaches were helpful as suggested by mean [average] scores of 3.68 to 3.78 on a range of 1 not helpful to 5 very helpful.

Table 3
How Helpful was the Educational Approach?

Descriptive Statistics			
	N	Mean	Std. Deviation
Post0301 Presentations	190	3.78	1.256
Post0302 Round tables/Speed Dating	168	3.68	1.390
Post0303 One on one conversations	173	3.77	1.300
Post0304 Videos	169	3.75	1.248

Summary and Conclusions for Community-Oriented Event

This community-oriented event that focused on education about precision medicine and on recruitment for the *All of Us* Research Program, provide valuable information about the educational approaches needed by community members. Comparisons before and after the educational session indicated more awareness afterwards. Likelihood to participate in such a program was also noted to increase slightly after the educational session. None of the four educational approaches seemed to be more favored than another and so it is recommended that other approaches be added that may be more influential.