Published in final edited form as:

Prog Community Health Partnersh. 2016 ; 10(4): 569–576. doi:10.1353/cpr.2016.0065.

Engaging Study Participants in Research Dissemination at a Center for Population Health and Health Disparities

Sarah Knerr^{1,2}, Sarah D. Hohl^{1,3}, Yamile Molina^{1,4}, Marian L. Neuhauser^{1,5}, Christopher I. Li^{1,5}, Gloria D. Coronado⁶, Stephanie M. Fullerton^{1,7}, and Beti Thompson^{1,3}

¹Fred Hutchinson Cancer Research Center, Public Health Sciences Division

²Group Health Research Institute

³Department of Health Services, University of Washington School of Public Health

⁴Community Health Sciences Division, University of Illinois-Chicago School of Public Health

⁵Department of Epidemiology, University of Washington School of Public Health

⁶Kaiser Permanente Center for Health Research

⁷Department of Bioethics & Humanities, University of Washington School of Medicine

Abstract

Background—Research dissemination is a priority for The Partnership for Understanding and Eliminating Disparate Outcomes (PUEDO) for Latinas, a Center for Population Health and Health Disparities located at the Fred Hutchinson Cancer Research Center (FHCRC).

Objectives—We aimed to identify types of PUEDO research findings our participants wanted and why, dissemination audiences beyond PUEDO participants, and strategies to communicate diverse findings about breast cancer and breast cancer disparities.

Methods—Five focus groups with PUEDO study participants ($N = 25$) were transcribed for qualitative content analysis (average participants per focus group, 5; range, 2–11).

Results—Participants reported wanting to learn aggregate and personal results and were influenced by their life experiences, their experiences as study participants, and the relevance they believed specific results would have for their lives. Women advocated for broad dissemination and inclusive communication using a simple paper-based strategy that would be accessible to diverse audiences (e.g., study participants, policymakers, recent immigrants).

Conclusions—Focus groups informed PUEDO's dissemination strategy, which concentrates on study participants and the regional Latino community. This approach to dissemination should maximize information uptake and community benefit.

Keywords

Community health partnerships; health disparities; breast neoplasms; ethics; health promotion

The Centers for Population Health and Health Disparities (CPHHD) program was created by the National Institutes of Health to accelerate scientific progress on health disparities through transdisciplinary (TD) research.^{1,2} The CPHHD's TD approach combines evidence and methods culled from many disciplines to understand and address disparities at multiple levels of analysis, with the expectation that resulting strategies will be comprehensive and more effective than solutions from a single discipline.³ The CPHHD program also emphasizes community-engaged and translational research approaches to help close research discovery–program delivery gaps in understanding and addressing health disparities.²

Research dissemination is an essential component of both community-engaged research and evidence translation.^{4–6} The former is concerned with communicating results back to the community as a means of knowledge integration and co-learning,⁷ and the latter focuses on the targeted distribution of evidence-based information and interventions to specific clinical or public health audience.⁸ Although these two types of dissemination differ in some ways, they both involve reaching audiences beyond traditional academic spheres. Emphasizing the need for this type of active engagement, the request for funding applications instructed CPHHDs to facilitate dissemination of evidence emerging from their projects and to plan for results dissemination.⁹ Herein, we describe how PUEDO, a CPHHD based at the Fred Hutchinson Cancer Research Center (FHCRC) in Seattle, Washington, is approaching dissemination.

PUEDO's overarching goals are to elucidate the complex causes of breast cancer disparities between Latina and non-Latina white women and determine how to best intervene to reduce outcome gaps. These goals are addressed through four interrelated projects. *Fortaleza Latina* (n = 541) seeks to increase mammography among Latinas attending safety-net clinics through a multilevel intervention strategy that includes motivational interviewing delivered by health educators. *Comparing Original Mexican Diets and Standard US Diets (COMIDAS)* is an experimental controlled feeding study assessing diet-related breast cancer precursors in Latina women (n = 50). *Breast Cancer Risk and Various Outcomes (BRAVO)* (n = 1,206) is a population-based case–case study examining predictors of aggressive breast cancer subtypes, including triple negative and HER2 overexpressing cancers. Finally, the *Collaboration to Study Hispanic Ancestry and Cancer Outcomes (CHACO)* explores the relationship between breast cancer subtypes and established risk factors using anonymized tumor samples collected from Hispanic participants at the University of New Mexico, a PUEDO partner institute. BRAVO and CHACO also consider the role of genetic characteristics, including ancestry informative markers, in breast cancer etiology. A community advisory board (CAB) helps to ensure that PUEDO's projects are informed by the experiences and perspectives of Latina women and their families as well as individuals and organizations working to address breast cancer disparities in our region and New Mexico. The CAB is therefore comprised of members of these organizations and groups (e.g., community health department, Latino service agency) as well as a breast cancer survivor.

Beginning in 2013, PUEDO's investigators and CAB members developed a plan to recontact participants in the three projects that involved patient recruitment to gather information to guide dissemination efforts using focus groups. The decision to return to participants in this

way was based on our prior experiences with community-based participatory research and the belief that engaging directly with stakeholders to glean their beliefs, preferences, and advice would result in the most relevant and effective dissemination strategy with the greatest information uptake.^{7,10} We also posited that dissemination needs might vary across the diverse study populations enrolled in the three projects, ranging from mammogram-eligible low-income Latina women to breast cancer survivors of any ethnicity. This paper describes our work to engage PUEDO study participants broadly around results dissemination.

METHODS

Participant Recruitment

All participants who had taken part in the Fortaleza Latina, COMIDAS, and BRAVO studies and signed a future contact release were eligible for the focus groups. Respective study staff invited former participants to take part in the current study through phone calls, mailed letters, and email. Participants were provided the option to join a Spanish- or English-language focus group.

Data Collection and Analysis

The research team developed a five-question survey of basic demographic and health information seeking characteristics and a focus group moderator guide. Ten open-ended questions aimed to elicit perspectives about the potential PUEDO findings participants wanted to learn about and why, other audiences participants believed would benefit from learning PUEDO results, and strategies for conducting dissemination. All materials and procedures for the focus groups were approved by the FHCRC Institutional Review Board.

Fortaleza Latina focus groups were held at two local clinics that had participated in the intervention study. COMIDAS and BRAVO focus groups were held at the FHCRC, where prior research activities had largely been conducted. English-speaking focus groups were conducted by the center director and Spanish-speaking focus groups were conducted by a bilingual, bicultural member of the study team. Focus groups lasted approximately 1 hour and were audio-recorded using a digital recorder. Participants provided written informed consent and received a \$25 gift card for their time.

Spanish audio files were transcribed and translated by a professional service and English focus groups were transcribed by members of the project team. All files were checked for accuracy and uploaded into Atlas.ti Version 7 (Berlin, Germany) for analysis. Three members of the research team each independently reviewed three focus group transcripts. Each focus group was coded by at least two team members. Through an iterative process the coding team applied both deductive qualitative content analysis, where broad code categories were identified based on four content areas covered in the interview guide¹¹ (i.e., what, why, who, how) and inductive thematic analysis, where overarching themes across content areas were derived from participants' responses to questions posed during the focus groups.¹² The coders met regularly to discuss and agree on a final codebook to apply across all focus group transcriptions. Codes were compared to determine patterns and identify how

responses varied across focus groups. The coders engaged in peer debriefing by presenting themes and categories to the larger research team as well as the PUEDO CAB, who each aided in interpretation of focus group findings.¹³

RESULTS

Twenty-five participants agreed to participate in a focus group between February and April 2013. Overall, five focus groups were conducted with former PUEDO study participants (average participants per focus group, 5; range, 2–11). Table 1 provides basic demographic and health information-seeking characteristics for the sample. Emergent themes were grouped into four overarching categories corresponding to the main content areas covered in the focus group guide. Table 2 summarizes key themes and provides illustrative quotations.

What Study Findings Participants Want

Across focus groups, women said that they were interested in receiving all types of potential PUEDO findings. As one respondent from COMIDAS noted, “Projects and investigations about health, I am interested in any kind of thing as long as I can learn something.” Similarly, a BRAVO participant confirmed, “The more information the better.” Participants expressed a desire for aggregate results from the studies in which they had participated as well as other PUEDO studies and also said they wanted to know how PUEDO findings could be implemented or inform future research. In addition to aggregate results, participants said they wanted to learn personal results like their own risk of breast cancer recurrence or risk of obesity or diabetes. One COMIDAS participant suggested, “It would be great if you could say, ‘In [participant’s name] we found that—this is your result and this is what we found.’” However, many BRAVO focus group participants, who had taken part in prior research studies, were quick to point out that in their experience receiving individualized results of this nature was unlikely and would have been explicitly discussed and consented to during study enrollment.

The specific types of results focus group participants said they were most interested in receiving depended on the original project in which they had participated, but was often unrelated to the project’s scientific aims and instead reflected the populations’ informational or health care needs. For example, Fortaleza Latina participants wanted to know about other programs or extensions of the Fortaleza Latina intervention that could provide patient navigation, education, and/or free mammography services, and BRAVO participants expressed a desire for any information that could illuminate why they had suffered from aggressive breast cancer and how they could prevent it from recurring.

Why Participants Want Study Results

Focus group participants shared many common reasons for wanting to learn PUEDO results, such as curiosity, reciprocity, the desire to inform their own behavior, and the desire to share information with others. A Fortaleza Latina respondent told us, “The more information we have, the more we can try and motivate people.” When describing why they wanted the specific types of results they perceived as most important, women were influenced by their life experiences, their experiences as study participants, and the relevance they believed

those specific results would have for their lives. Thus, motivations for wanting to learn specific PUEDO findings varied between the projects. Fortaleza Latina participants wanted results so they could help other women overcome barriers to accessing breast cancer screening. COMIDAS participants were motivated by curiosity—many had developed their own hypothesis about which of the two diets being investigated led to better health outcomes over the course of the study and wondered if they were correct. BRAVO women, as cancer survivors, were motivated by a strong fear of recurrence. One BRAVO participant reported, “I think that’s our biggest worry is that after you go through treatment, you know, you survived it ... what can we do now to prevent recurrences of cancer?”

Proposed Audiences for Dissemination

Women across all focus groups agreed that audiences beyond former study participants could benefit from learning PUEDO’s ultimate findings. Participants identified several audiences for broader dissemination, including participants’ families, younger generations, Latinos, and the general public. Each focus group also suggested unique audiences for dissemination, typically reflecting groups for whom they perceived their own study’s results would be directly relevant. Respondents who had participated in the Fortaleza Latina and BRAVO projects, which focused specifically on breast cancer, more often emphasized the importance of delivering study findings to women, particularly daughters, other female relatives, and friends. Fortaleza Latina participants also suggested that their study’s results should be communicated back to their local health clinic, particularly to social workers, who they believed were most well-equipped to implement findings in practice. COMIDAS participants thought their study’s results could be particularly useful for migrant Latinos and new immigrants. They also identified their study’s potential policy implications and suggested relaying results to officials who set school lunch policies, hospitals, and restaurants.

Proposed Strategies for Dissemination

Focus group participants provided several suggestions for communicating study results to the diverse audiences they suggested for dissemination. Despite the fact that the focus group participants had different primary languages and ways of accessing health information, all focus groups conveyed a clear message: for dissemination to be successful, it must be accessible to a range of audiences. For example, a Fortaleza Latina participant emphasized that materials should be, “the most simple as possible so they can understand. Sometimes not all of us have the same capabilities.” To accomplish the goal of inclusivity, women suggested that PUEDO communications should be brief and simple, but include ways for individuals to access more detailed information if interested. All focus groups advocated for using primarily paper-based communication (e.g., fliers, newsletters, mailings), but including links and references to other modalities (e.g., online and phone resources). Women also said the media (e.g., print, radio, web-based) could be a powerful tool to disseminate PUEDO results and also suggested tabling at local events and community locations.

Notable differences in proposed dissemination strategies also existed across focus groups. COMIDAS and BRAVO focus groups included a number of women who had previously participated in research and/or worked in health care. These focus group participants said

they were interested in receiving results in a way that was similar to how they would be conveyed to the scientific community. Some women specifically requested copies of reports and published manuscripts and said they would actively seek out these types of products online. COMIDAS and BRAVO participants also proposed that researchers hold a conference where PUEDO results would be presented to former study participants and their families. In contrast, Fortaleza Latina participants, who had little prior exposure to research, emphasized their desire for simple information and basic messages. Fortaleza Latina participants also explained that they would need their children's help to take advantage of any dissemination strategy that relied on the Internet.

DISCUSSION

PUEDO's efforts to engage with participants about dissemination provided us with rich primary data to share with our CAB and investigators. We presented focus group results to the CAB and PUEDO investigators in September 2014. PUEDO investigators had been supportive of an active approach to dissemination in response to the CPHHD request for funding application, but also wanted to communicate findings to participants to thank them and show them what emerged from their efforts. The focus group results reinforced this commitment. The CAB was supportive of our plans to disseminate PUEDO findings to participants and echoed PUEDO participants' concerns about inclusiveness. They agreed that a simple, paper-based approach that included links to online resources would address this. The CAB also encouraged us to invite former participants to review dissemination materials and advocated for a much broader scope of outreach activities, including working with local clinics to expand access to mammography for Latina women, addressing social determinants of health that shape Latinas' access to care and breast cancer outcomes in our area, conducting in-service trainings with medical professionals working with Latinas around breast cancer prevention and screening, engaging former participants in ongoing research and advocacy activities, and providing former participants with health promotion information via text messaging.

The dissemination plan we developed builds on the focus group results as well as the feedback we received from our CAB (Table 3). We will primarily rely on a newsletter reporting aggregate findings from all PUEDO studies in plain language. Recent studies of Latinos' research dissemination preferences have suggested that while favored communication methods (i.e., over the phone, in person, through the mail using printed materials, via text message) are setting and context dependent, simple low-technology approaches like typed letters are widely accepted.^{14,15} Despite the interest in personal results we saw in the focus groups, the decision was made to report only aggregate findings due to the substantial logistical and ethical issues involved in returning personalized research results.^{16,17} Additionally, most PUEDO informed consent forms did not allow for return of individual results. Newsletters will encourage participants to discuss findings with their friends and family members and include the PUEDO web address for those interested in additional information. The website will provide a place to link to PUEDO publications and announce PUEDO-related events that are open to the public. To expand dissemination reach, we plan to distribute the newsletters in the clinics that participated in the Fortaleza Latina intervention study, community locations in our area, and health fairs targeting the growing

Latino population in Eastern Washington State. Finally, we intend to use FHCRC resources to present PUEDO results to the media and to include PUEDO investigators in an existing cancer health disparities speakers bureau to communicate PUEDO findings to community organizations, other academics, and policymakers.

We encountered a number of challenges that have implications for the dissemination of TD health disparities research more broadly. Although returning aggregate and individual research results back to study participants seems to be occurring more frequently,^{18,19} many practical barriers remain. These include both time and financial constraints.^{6,20} We addressed resource issues by seeking additional funding for dissemination, taking advantage of existing services at our institution for media relations, and concentrating on free or low-cost dissemination methods. These are strategies that may or may not be available in other settings, but require foresight and preparation early in the research planning process. We also encountered ethical challenges that required careful consideration. For example, we struggled with how to disseminate the different types of results that PUEDO may produce, which range from novel genetic associations to statistical assessments of intervention efficacy and cost effectiveness, in a way that is transparent, but also contextualized within the larger evidence base, so as to not contribute to hype or misinformation.^{21,22} We relied on our CAB's input and expertise to address this issue—they, along with the FHCRC Institutional Review Board, will review all dissemination materials. Returning to participants for their input, as our CAB originally suggested, would be ideal, but in some ways scientifically compromised if dissemination materials are based on well-validated approaches and tested theories. More thought on best practices for disseminating findings from large-scale research projects where results range from preliminary to immediately translatable to clinic or population-level use is warranted. Combining dissemination techniques from community-based participatory research, where the desire for open communication must be balanced with the commitment to do no harm, and dissemination science may help to generate novel approaches most appropriate for TD health disparities research.²³

Finally, we encountered challenges that were a byproduct of our decision to go back to participants to talk about dissemination. Learning about participant needs that were beyond the scope of PUEDO's dissemination goals and resources, for example, was one side effect of asking participants to tell us their main concerns during the focus groups. Furthermore, when we conveyed the focus group results to the CAB, we saw that these unmet needs then overshadowed the larger conversation about disseminating the specific research results that PUEDO would generate about breast cancer. These types of challenges may explain, in part, why a systematic review of dissemination in community-based participatory research studies found that although returning study results to community participants was an almost universal practice, only 42% of the identified articles described involving the community in their dissemination efforts.²⁰ We addressed these issues by engaging in reflective discussion about PUEDO's ultimate goals for dissemination, reorienting ourselves to these goals, and recognizing that we could use the data we had collected on community preferences and needs as groundwork to inform future research projects. Waiting to conduct focus groups when specific study results are available, rather than discussing potential results or asking participants broadly about their informational needs and priorities, could be one way to

minimize this issue in future studies. Still, this could prove difficult on typical grant timelines, which often do not include dedicated resources or infrastructure for dissemination after projects have ended.

CONCLUSIONS

Engaging with participants throughout the research process is an effective strategy for informing research dissemination efforts as it provides important primary data to help investigators to create relevant and effective strategies with broad reach. Our focus groups findings showed that research participants value learning study results and are beginning to expect it from investigators and institutions. Our participants said they were eager to participate in future studies when they knew their efforts had contributed to important scientific discoveries. Successful dissemination informed by continued participant engagement is essential for building and sustaining trusting relationships between TD researchers and communities experiencing health and health care disparities.

Acknowledgments

Supported by grant P50CA148143 from the National Cancer Institute. Dr. Knerr was supported by a post-doctoral fellowship from the National Institute on Aging (T32AG027677).

References

1. Centers for Population Health and Health Disparities (CPHHD). Cells to society: Overcoming health disparities [updated 2007]. Available from: http://cancercontrol.cancer.gov/populationhealthcenters/cphhd/documents/CPHHD_report.pdf
2. Warnecke RB, Oh A, Breen N, et al. Approaching health disparities from a population perspective: The National Institutes of Health Centers for Population Health and Health Disparities. *Am J Public Health*. 2008; 98(9):1608–15. [PubMed: 18633099]
3. Hall KL, Vogel AL, Stipelman BA, et al. A four-phase model of transdisciplinary team-based research: goals, team processes, and strategies. *Transl Behav Med*. 2012; 2(4):415–30. [PubMed: 23483588]
4. Brownson, RC., Colditz, GA., Proctor, EK. Dissemination and implementation research in health: Translating science to practice. New York: Oxford University Press; 2012.
5. Harris JR, Cheadle A, Hannon PA, et al. A framework for disseminating evidence-based health promotion practices. *Prev Chronic Dis*. 2012; 9:E22. [PubMed: 22172189]
6. Kerner J, Rimer B, Emmons K. Introduction to the special section on dissemination: dissemination research and research dissemination: how can we close the gap? *Health Psychol*. 2005; 24(5):443. [PubMed: 16162037]
7. Israel BA, Schulz AJ, Parker EA, et al. Review of community-based research: assessing partnership approaches to improve public health. *Annu Rev Public Health*. 1998; 19:173–202. [PubMed: 9611617]
8. Glasgow RE, Vinson C, Chambers D, et al. National Institutes of Health approaches to dissemination and implementation science: current and future directions. *Am J Public Health*. 2012; 102(7):1274–81. [PubMed: 22594758]
9. National Institutes of Health (NIH). Request for Applications [updated 2008]. Available from: <http://grants.nih.gov/grants/guide/rfa-files/RFA-CA-09-001.html>
10. Thompson B, Coronado G, Puschel K, et al. Identifying constituents to participate in a project to control pesticide exposure in children of farmworkers. *Environ Health Perspect*. 2001; 109(Suppl 3):443–8.

11. Cho JY, Lee EH. Reducing confusion about grounded theory and qualitative content analysis: Similarities and differences. *Qual Report*. 2014; 19(32):1–20.
12. Corbin, J., Strauss, A. *Basics of qualitative research: Techniques and procedures for developing grounded theory*. 3rd. Thousand Oaks (CA): Sage; 2007.
13. Miles, MB., Huberman, AM. *Qualitative data analysis: An expanded sourcebook*. 2nd. Thousand Oaks (CA): Sage; 1994.
14. Lajonchere CM, Wheeler BY, Valente TW, et al. Strategies for disseminating information on biomedical research on autism to Hispanic parents. *J Autism Dev Disord*. 2016; 46:1038–50. [PubMed: 26563948]
15. Sandberg JC, Spears Johnson CR, Nguyen HT, et al. Mobile and traditional modes of communication among male Latino farmworkers: Implications for health communication and dissemination. *J Immigr Minor Health*. 2016; 18(3):522–31. [PubMed: 26463228]
16. Bledsoe MJ, Grizzle WE, Clark BJ, et al. Practical implementation issues and challenges for biobanks in the return of individual research results. *Genetics Med*. 2012; 14(4):478–83. [PubMed: 22323073]
17. Fabsitz RR, McGuire A, Sharp RR, et al. Ethical and practical guidelines for reporting genetic research results to study participants updated guidelines from a National Heart, Lung, and Blood Institute working group. *Circulation Cardiovasc Genetics*. 2010; 3(6):574–80.
18. Darbyshire JL, Price HC. Disseminating results to clinical trial participants: a qualitative review of patient understanding in a post-trial population. *BMJ Open*. 2012; 2(5):e001252.
19. Dressler LG. Disclosure of research results from cancer genomic studies: state of the science. *Clin Cancer Res*. 2009; 27:41.
20. Chen PG, Diaz N, Lucas G, et al. Dissemination of results in community-based participatory research. *Am J Prev Med*. 2010; 39:372–8. [PubMed: 20837290]
21. Wilson PM, Petticrew M, Calnan MW, et al. Disseminating research findings: What should researchers do? A systematic scoping review of conceptual frameworks. *Implement Sci*. 2010; 5:91. [PubMed: 21092164]
22. Malen R, Knerr S, Delgado F, et al. Rural Mexican-Americans' perceptions of family health history, genetics, and disease risk: Implications for disparities-focused research dissemination. *J Community Genetics*. 2016; 7:91–6. [PubMed: 26141228]
23. Trinidad SB, Ludman EJ, Hopkins S, et al. Community dissemination and genetic research: Moving beyond results reporting. *Am J Med Genetics A*. 2015; 167(7):1542–50. [PubMed: 25900516]

Table 1

Focus Group Demographic and Health Information-Seeking Characteristics

Original PUEDO Study and Focus Group Language	Fortaleza Latina			COMIDAS		BRAVO	
	Spanish, <i>n</i> (%)	Spanish, <i>n</i> (%)	English, <i>n</i> (%)	Spanish, <i>n</i> (%)	English, <i>n</i> (%)	Spanish, <i>n</i> (%)	English, <i>n</i> (%)
Participants (<i>n</i>)	3	3	2	6	11		
Age (yrs)							
18–39	0 (0)	0 (0)	1 (50)	2 (33)	0 (0)		
40–64	3 (100)	2 (66)	1 (50)	4 (67)	9 (82)		
65–75	0 (0)	1 (33)	0 (0)	0 (0)	2 (18)		
Uses a computer to get health information on the Internet	0 (0)	1 (33)	2 (100)	6 (100)	10 (91)		
Uses a cell phone to get health information on the Internet	0 (0)	2 (67)	1 (50)	5 (83)	1 (9)		
Uses email at least once a week	0 (0)	1 (33)	2 (100)	6 (100)	11 (100)		

Abbreviations: BRAVO, Breast Cancer Risk and Various Outcomes; COMIDAS, Comparing Original Mexican Diets and Standard US Diets; PUEDO, The Partnership for Understanding and Eliminating Disparate Outcomes for Latinas.

Percentages may not sum to 100 due to rounding.

TABLE 2

Themes and Illustrative Quotations from PUEDO Focus Groups

What study-related information participants want	
Aggregate results	Yes, of course it would be interesting to see the differences [between PUEDO project findings]. I think that's a good idea. I also think it would be interesting. (Fortaleza Latina) General information is very important as well to show it to the public because you will be able to know how good our Mexican food is and how good is the American food. (COMIDAS)
Personal results	Yeah, it would be nice to know about my own, you know, myself. (COMIDAS)
Next steps for research implementation	[If the clinics get the results] ... they can help too and they can prevent it or provide more information to us in Spanish, so that we can prevent cancer. (Fortaleza Latina) It's interesting because the COMIDAS study for the food portion was not necessarily as in-depth with the breast cancer as the other three were. So, I think it would be interesting knowing that there's that dietary portion of it, that go into those three other ones and being able to learn about, well, how much does it play into it? And, what can we learn from all the data that we've gathered?(COMIDAS)
General information and services to prevent cancer recurrence and incidence in their community	... to know if there are other programs like Fortaleza Latina that can help women in other areas. (Fortaleza Latina) I want to make sure I'm doing everything to stay healthy.... I don't really want to really go through this again. And it seems like, that, um, there's a lack of information there. So that would be good to focus on that kind of stuff. So, those preventable, kind of, risk factor groups are very, yeah, very important. (BRAVO)
Common motivations: curiosity, reciprocity, desire to inform behavior, desire to share information with others	I think it's important [to disseminate results to the community] so they can see how easy it is to be fine in terms of health. Because if they realize what we have gone through, they will say, 'Oh! I don't want to go through what she went through. I want to be [screened] on time. For me and for my family and for all the people who surround me.' (Fortaleza Latina) But knowing that information has to be sent to me — whichever way you guys decide to do that, um, it's much more of, it is satiating curiosity. (COMIDAS) Regardless if it's specific to you, it's nice to know what the study changed. (BRAVO) So I think we are interested even if it's not going to impact our personal choices at this point, but it's interesting to know. And then we're interested if there's anything, you know, that we can do now: changes in behavior, diet, whatever. There's two parts ... " (BRAVO).
Study-specific motivations: barriers to accessing health care, dietary guidelines, risk of recurrence	It's just interesting to find out which diet really will help you to lose weight or maybe to not lose weight. Is one really better than the other? (COMIDAS) What I found is that after I was diagnosed and treated is, it's like, 'Okay, I'm going to be around for a while, so what can I do to prevent the cancer from spreading?' And — and it's kind of, you know, they all say, 'Well, eat right and exercise and reduce stress.' It's like, 'okay' Um, but it — it seems like there's a lot that we don't know about, um, you know, helpful behavior systems. (BRAVO)
Proposed audiences for dissemination beyond PUEDO participants	
Family, community, health clinics	There's always been quite a dilemma with the diet at public schools and they never change it so maybe they should be informed that, for example, this is not as nutritive as this, as is show in the results of our study, whether it's the American or the Mexican diet. Maybe they would feel more pressure to finally change their diets (COMIDAS). I would be really interested in that, because *pause* it's one thing to — to get this information and then, you know, try to convey it to my daughter (BRAVO)
Proposed strategies for dissemination	
Simple, paper-based with links to media sources or publications	Everything that is transmitted through the internet, radio, TV reaches every home in the world (Fortaleza Latina) Well, I would actually prefer a report; something that's a little more in-depth ... (COMIDAS) There's a couple of studies that have actually sent a copy of the published literature, which is great because, you know—LOOK—I—THIS IS ME! I DID THIS! (BRAVO)

Abbreviations: BRAVO, Breast Cancer Risk and Various Outcomes; COMIDAS, Comparing Original Mexican Diets and Standard US Diets; PUEDO, The Partnership for Understanding and Eliminating Disparate Outcomes for Latinas.

Table 3

The Partnership for Understanding and Eliminating Disparate Outcomes (PUEDO) for Latinas Results Dissemination Plan

Level of Influence	Target Audience	Dissemination Strategy
Individual	Participants	Distribute newsletters through mail using last known address
Interpersonal	Participants' families and social networks	Encourage broad sharing of results in newsletter text
Organizational	Clinics	Present findings at WA state community health worker meeting Distribute newsletters to Fortaleza Latina clinics
Community	WA residents	Distribute newsletters to mobile mammography vans, community locations, health fairs
	General public	Post results and manuscripts on PUEDO website Media outreach working with FHCRC communications
Public policy	Breast cancer experts and advocacy organizations; state and federal policy-makers	Participate in FHCRC cancer disparities speakers bureau

Abbreviations: FHCRC, Fred Hutchinson Cancer Research Center; PUEDO, The Partnership for Understanding and Eliminating Disparate Outcomes for Latinas; WA, Washington.