



Research paper



“The results are encouragements to make positive changes to be healthier:” qualitative evaluation of Marshallese participants’ perceptions when receiving study results in a randomized control trial

Pearl A. McElfish^{a,*}, Rachel S. Purvis^b, Aaron J. Scott^c, Lauren K. Haggard-Duff^d, Sheldon Riklon^c, Christopher R. Long^b

^a University of Arkansas for Medical Sciences Northwest, Fayetteville, AR, United States

^b College of Medicine, University of Arkansas for Medical Sciences Northwest, United States

^c Office of Community Health and Research, University of Arkansas for Medical Sciences Northwest, United States

^d College of Nursing, University of Arkansas for Medical Sciences Northwest, United States

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ABSTRACT

Background: Study participants express a desire to receive the results of studies in which they have participated even when the results are not what researchers expected. Sharing results with participants is a core principle of community-based participatory research (CBPR), however, many researchers using a community-based participatory approach report that they encounter barriers to sharing results with study participants. Researchers at the University of Arkansas for Medical Sciences established a CBPR partnership with Marshallese community stakeholders in an effort to reduce the health disparities of this vulnerable population. Marshallese are a Pacific Islander population that faces significant health disparities and have a high prevalence of diabetes, obesity, obesity-related cancers, and other chronic diseases compared to the general US population.

Methods: A qualitative descriptive design was used to evaluate Marshallese participants’ perceptions related to receiving results of a culturally adapted Diabetes Self-Management Education randomized control trial in which they participated. Participants were provided with a summary of their individual results as well as preliminary, overall aggregate study results. Interviews were conducted with half of (N = 111) of the 221 enrolled participants that provided them with the opportunity to share in-depth responses related to their perceptions of the study results they received.

Results: There was no statistically significant differences between study arms in participant desire to receive overall study results, desire to receive personal study results, or willingness to participate in future research. Participants described their desire for results and the effect of these results on their future behavior. Within the *a priori* theme of participants’ desire for results, three subthemes emerged: 1) results showed current health status, 2) results showed improvement, and 3) demonstrated the overall results of the study. Within the *a priori* theme of effects of results on future behavior, two sub-themes emerged: 1) encourage future healthy behavior, and 2) encourage future research participation.

Conclusions: Participants overwhelmingly stated they wanted to receive personal and aggregate study results. This finding is consistent with previous qualitative studies that documented that participants want results. Marshallese participants also reported that receiving study results would affect their future health behavior. This study documents specifically how participants anticipate using the results of studies in which they participated.

Clinical trials registration information: The study is registered in clinicaltrials.gov (#NCT02407132).

1. Introduction

Marshallese are a Pacific Islander population that has migrated to the

United States seeking greater opportunities for employment, education, and health care. Marshallese adults face significant health disparities and have a high prevalence of diabetes, obesity, obesity-related cancers,

* Corresponding author.

E-mail address: pamcelfish@uams.edu (P.A. McElfish).

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and other chronic diseases compared to the general US population [1–6]. Northwest Arkansas is home to the largest population of Marshallese in the continental United States with approximately 12,000 Marshallese migrants [7]. A local needs assessment found that Marshallese adults (N = 401) had an extremely high incidence of type 2 diabetes (38.4%) and prediabetes (32.6%) as well as high incidence of hypertension (41.2%) and prehypertension (39.1%) [2]. Furthermore, many Marshallese are uninsured or underinsured, which exacerbates their health disparities by limiting their access to preventive and primary care [2]. Researchers at the University of Arkansas for Medical Sciences (UAMS) established a community-based participatory (CBPR) partnership with local Marshallese community stakeholders in an effort to reduce the health disparities of this population [8–15].

The CBPR approach allowed researchers to build trust with the Marshallese community that is skeptical of health research due to historical trauma. From 1946 to 1958, the US military conducted extensive nuclear weapons testing that devastated the natural environment and exposed Marshallese to nuclear radiation [16,17]. After the weapons testing, US scientists conducted Project 4.1 to research the effects of nuclear exposure on humans; however, study materials were not translated into Marshallese, and the research was conducted without the informed consent of Marshallese participants [16]. UAMS researchers have been successful in addressing the distrust stemming from the historical trauma experienced by the Marshallese community by building academic-research partnerships with Marshallese community stakeholders [15].

Marshallese community stakeholders selected diabetes as the primary issue to address, and then collaborated with researchers to design a culturally adapted diabetes self-management education (DSME) intervention that incorporated family members that was tested in a randomized controlled trial (RCT) [3,18,19]. Marshallese stakeholders partnered with researchers on all aspects of the research design; they helped define the research question, provided insight on cultural adaptation of the intervention, and collaborated on best practices for participant recruitment and engagement as well as dissemination of study findings [18,19]. A sample of 221 Marshallese participants with type 2 diabetes were randomized to either the culturally adapted DSME arm that incorporated family members or the standard DSME arm conducted in a community setting [18]. Participants in both arms received 10 h of DSME content focused on eight main themes that included: healthy eating, physical activity, glucose monitoring, understanding blood glucose and taking medications, problem solving, reducing risks and healthy coping, mitigating complications of diabetes, and goal setting. The primary outcome measure was change in participants' A1C. Full descriptions of the study design, protocol, and outcomes are reported elsewhere [3,18].

There is evidence demonstrating that research participants want to receive the results from studies in which they participate [20–27], even if the results are not what the researchers expected to find [22]. Despite participants' desire to receive results, many researchers acknowledge they often do not provide results to study participants [27–30]. Multiple barriers often impede researchers' ability to share study results, including financial, logistical, methodological, and systems barriers [31]. Some funding agencies like the National Institutes of Health (NIH), the Patient-Centered Outcomes Research Institute (PCORI), and the Agency for Healthcare Research and Quality (AHRQ) encourage sharing research results with participants and the public in an effort to make research more accessible [32–34]. Sharing results with study participants is a core principle of CBPR, which incorporates participants and stakeholders in every aspect of research from study design and implementation, to the dissemination of findings [35]. However, many CBPR researchers report that they do not share results with participants [28]. The authors are committed to ensuring dissemination of research results to participants of their studies [26,27,31,34,36,37]. As the CBPR research team disseminated study findings to participants, the participants' perceptions related to receiving the results of the study were

evaluated. This article documents Marshallese participants' responses to receiving personal biometric results and overall aggregate study results.

2. Methods

2.1. Randomized controlled trial

Inclusion criteria for the RCT were that participants be Marshallese adults aged 18 years or older who had a type 2 diabetes diagnosis or be a family member of the participant with diabetes. Participants provided written informed consent to enroll in the study. Biometric data were collected at four time points during the RCT: baseline, immediately after the intervention (9 weeks), six months post intervention, and 12 months post intervention. Study procedures were reviewed and approved by the University of Arkansas for Medical Sciences' Institutional Review Board (#203482). The study is registered in clinicaltrials.gov (#NCT02407132). A complete description of the study design and protocol is available [18]. Full description of quantitative analysis of the RCT results is reported elsewhere [3].

2.2. Qualitative evaluation

Data were collected from half (111) of the 221 Marshallese participants who enrolled in both arms of the culturally adapted DSME RCT through interviews. At the final 12-month study visit, participants were provided with a summary of their individual biometric results as well as preliminary, overall aggregate study results. Study staff presented participants with a handout of their individual biometric results collected during the RCT that reported their glucose, A1C, height, weight, blood pressure, and total cholesterol in a table format. On the other side of the handout, participants were provided with reference ranges for blood pressure, total cholesterol, LDL cholesterol, HDL cholesterol, triglycerides, glucose, and A1C. Study staff reviewed individual biometric results and showed participants where they fell on the reference ranges provided. If necessary, study staff provided referral services to participants who needed further assistance reaching recommended ranges. Overall study results for change in A1C from pre-to immediate post-intervention (9 weeks) were also provided to participants in a handout that reported the number of total participants, the number of participants assigned to each study arm, and the aggregated biometric data. A graph was included to show a mean reduction in A1C for both study arms but a larger reduction among participants in the family model arm. The graph was accompanied by a written summary in Marshallese and English that said the graph showed a significant reduction in A1C among family model participants and a smaller reduction in A1C among standard model participants. Participants were then invited to participate in an interview.

Three bilingual study staff members (two females and one male) conducted interviews in the Marshallese language in the participant's home or a private location of the participant's choice. The interview included both closed-ended (e.g., yes/no/not sure) and open-ended questions about participants' perceptions and experiences with receiving study results to allow participants to share in-depth responses related to their perceptions of the study results they received. Quantitative analysis were performed on closed-ended questions. Interviews lasted approximately 30 min. All interviews were audio recorded and transcribed verbatim. Interview transcripts were translated from Marshallese into English and then were verified by a bilingual study staff member. Participants were provided with a \$20 gift card as compensation for their participation in the interview.

A qualitative descriptive approach was used to examine interview data [38–40]. Qualitative descriptive design focuses on summarizing the experiences of participants and the meanings they ascribe to their experiences rather than focusing on theory development [38–40]. The research team began initial coding by naming each data segment with a short summary and then organized the data for more focused codes.

Codes were finalized and organized in a codebook. Transcripts were coded for both *a priori* and emergent themes. *A priori* themes were established by the open-ended questions on the interview guide that focused on participants' desire to receive results and the effect of the results they received on their future behavior. Two researchers with experience in qualitative methods coded the data independently and another confirmation coder reviewed and verified the coded data. The research team collaboratively discussed themes to ensure intercoder agreement. Marshallese staff also provided feedback on qualitative coding throughout the process to ensure that nuanced meanings of participants' responses were captured accurately.

3. Results

A total of 111 Marshallese participants completed an interview. The mean age of participants was 50.6 years (SD = 11.0) and 62.2% were female. Only 24.3% of participants reported having a primary care physician and less than half (39.6%) had health insurance coverage. Table 1 presents participants' characteristics. There were no statistically significant differences between study arms in desire for overall study results, desire to receive personal study results, or willingness to participate in future research ($p = 0.44, p = 0.44, p = 1.00$ respectively). See Table 2.

Qualitative data is presented under the two *a priori* themes: 1) Participants desire for results and 2) Effect of results on future behavior. The *a priori* theme of participants' desire for results is presented to show perceptions of participants' desire for personal results and participants' desire for aggregate study results. Within the *a priori* theme of participants' desire for results, three sub-themes emerged: 1) results showed current health status, 2) results showed improvements, and 3) demonstrated the overall results of the study. Within the *a priori* theme of effects of results on future behavior, two sub-themes emerged: 1) encourage healthy behavior, and 2) encourages research participation. Sub-themes that emerged under each *a priori* theme are presented. Table 2 reports responses to close ended-items from the interview guide.

3.1. Participants' desired results

3.1.1. Results showed current health status

Almost every participant (99.1%) reported that they wanted to receive their personal results. Participants stated that receiving their personal results was important because it showed them their current health status. One participant explained they wanted their personal results because "I want to know where I stand in regards to my health." (Standard Model [SM] PID 292) Another participant expressed a desire

Table 1
Participant characteristics and biometric results.

	Family DSME (N = 49)	Standard DSME (N = 62)	All Participants (N = 111)
Age	49.8 (11.6)	51.3 (10.6)	50.6 (11.0)
Female	27 (55.1)	42 (67.7)	69 (62.2)
Have a PCP	11 (22.4)	16 (25.8)	27 (24.3)
Have health coverage	18 (36.7)	26 (41.9)	62 (55.8)
A1C pre-intervention	10.9 (2.6)	10.4 (2.3)	10.6 (2.4)
A1C post-intervention ^a	9.8 (1.9)	10.0 (2.1)	9.9 (2.0)
A1C 12 months post-intervention	9.8 (2.3)	10.5 (2.5)	10.2 (2.4)
A1C difference ^b	-1.1 (2.5)	0.1 (2.4)	-0.4 (2.5)

Note: DSME = diabetes self-management education; PCP = primary care physician; A1C = Hemoglobin A1C.

^a A1C post-intervention (9-weeks): Family DSME N = 49, Standard DSME N = 59.

^b A1C difference = mean difference in A1C between pre-intervention and 12 month follow up. Mean (SD) or Count (%).

Table 2

Participant responses to Diabetes Self-Management Results Sharing after 12-Month Visit survey.

	Family DSME (N = 49)	Standard DSME (N = 62)	All Participants (N = 111)
Want overall study results			
Yes ^b	48 (98.0)	62 (100.0)	110 (99.1)
No	1 (2.0)	0 (0.0)	1 (0.9)
Want future personal test results			
Yes ^c	48 (98.0)	62 (100.0)	110 (99.1)
No	1 (2.0)	0 (0.0)	1 (0.9)
Will participate in future studies ^a			
Yes ^d	42 (85.7)	50 (83.3)	92 (84.4)
No	0 (0.0)	1 (1.7)	1 (0.9)
Maybe/Depends	7 (14.3)	9 (15.0)	16 (14.7)

^a Based on n = 109; Count (%).

^b Family vs Standard DSME, Fisher's Exact Test: $P = 0.44$.

^c Family vs Standard DSME, Fisher's Exact Test: $P = 0.44$.

^d Family vs Standard DSME, Fisher's Exact Test: $P = 1.00$.

for personal results "because I want to find out how my health is doing." (Family Model [FM] PID 411) Another participant explained they wanted their personal results "so I know if I am healthy or not [and because] I want to know and understand my results." (SM PID 281).

3.1.2. Results showed improvement

Participants also wanted to receive personal results so they could determine if their health status had improved during the course of the study. A participant explained that receiving personal study results allowed them "to know whether my diabetes is getting better or worse [so] I want to be able to review my own results." (FM PID 179) Other participants stated that viewing their personal results meant "I can see the different results from the first time and know if I am improving or not." (SM PID 184) Participants also explained they wanted their personal results "because I want to see all my numbers from the first time and compare it [to see if] I am improving or not," (FM PID 413) and "it's important for a person to know about their health so I can see if I am improving or not." (SM PID 373) Participants said they wanted their personal results because it would encourage them to improve their health status. As a participant explained, "I want to know where I am in my sugar level so I can take care of it." (FM PID 297) Another participant expressed "I want to have all my results to know where I am with my [biometric] readings; it will remind me to make it better." (SM PID 271).

3.1.3. Demonstrated the overall results of the study

Nearly every participant in both study arms (Family DSME 98.0%, Standard DSME 100.0%) reported that they wanted to receive aggregate study results. Obtaining aggregate study results was important to participants because they wanted to understand how the study was effecting the Marshallese community as a whole. They explained these results were important "because I want to know where Marshallese stand with diabetes," (SM PID 158) and "it is important to know if we [Marshallese] are improving or not" (SM PID 293). Participants also expressed that receiving aggregate study results allowed them to understand which treatment arm of the RCT was most effective and explained, "I want to know which one of these two groups is better for us." (SM PID 293) Most study participants' statements showed that they were able to interpret the aggregated study results, and stated that the aggregated results showed "that the family model is better than the other model" at lowering A1C. (FM PID 338) Participants stated that they wanted to obtain aggregate study results so that they could encourage themselves and others: "I want to see if we are improving on our numbers so we can find ways to help each other to come up with good results in the future," (SM PID 360) and "I think it's good to know where we are in our blood sugar level by looking at [the study] results so we will know what to do next" to improve the community's health status. (SM PID 240).

3.2. Effect of results on future behavior

3.2.1. Results encourage future healthy behavior

A common emergent theme that sharing results encourage future healthy behavior was expressed by participants from both treatment arms. Participants stated: “I know my results today, and I can make changes for my future lifestyle;” (SM PID 285) “my results will affect my future behavior because I will apply what I learned;” (FM PID 421) and “it gives me the courage to make changes to improve my health and the results are encouragements to make positive changes to be healthier.” (FM PID 268) Another participant expressed that seeing their personal biometric results was “good because they tell me if I need to improve my health and what areas I need to work on in order to have better health.” (SM PID 381) Others said receiving their personal results demonstrated their ability to manage their diabetes and encouraged them to continue with self-management behaviors: “Now I know that I can manage it;” (FM PID 180) it will “help me to do better in regards to my health from now on [and] especially making decisions to control my diabetes” (SM PID 277) and “it’s good to know what the results are to help maintain good numbers of [blood glucose], high blood pressure, and cholesterol.” (FM PID 170).

Participants also discussed specific examples of ways they would improve future health behaviors as a result of receiving their personal results from the RCT. These included eating healthy, increasing their exercise, improving their medication adherence, and seeing and communicating with a primary care physician. Participants explained, “I have to be more careful on what I am eating and drinking;” (FM PID 154) and that knowing their results will “help me to really control my eating habits, help me to exercise more, and so I can take my medications as prescribed.” (SM PID 158) One participant explained that they would now “exercise more and eat more vegetables” after reviewing their personal results. (SM PID 356) Another stated, “It will help me by encouraging me to be healthier, to exercise, and to eat healthier.” (FM PID 200) Another participant said, “I will prevent myself from eating too much and reduce my soda intake” after seeing their results. (FM PID 357) A few participants stated that their results encouraged them to talk to their primary care physician: “I will try to go see a doctor” (FM PID 295) and another wanted “a copy to review and to take to the doctor.” (FM PID 203).

3.2.2. Results encourage future research participation

A majority of participants (84.4%) reported that they would be interested in participating in future studies after receiving study results, and another 14.7% said they “maybe” would be interested in participating in future studies. Participants explained that obtaining study results “encourages me to participate in other studies in the future;” (SM PID 158) “It makes me want to participate in future studies;” (SM PID 269) “this makes me want to participate more in your future studies” (FM PID 143) and “I will be very happy to participate in the studies in the future.” (SM PID 186) Participants explained that receiving results increased their interest in future research participation because they “want to participate in any study that will help Marshallese people,” (SM PID 266).

4. Discussion

This study evaluated Marshallese participants’ perceptions related to receiving their personal biometric results and the preliminary, aggregate study results from a RCT in which they participated. Participants overwhelmingly stated they wanted to receive their personal study results as well as aggregate study results. Interestingly, there was no significant difference in these rates between the two study arms. This finding is consistent with a previous qualitative study that documented participants wanted study results regardless of the outcome of the study [20–27]. Marshallese participants felt the results helped them understand their current health status, and if the intervention had improved

their health status and the health of their community.

A second key finding was Marshallese participants reported that receiving both personal and aggregate study results would influence their future health behavior. Marshallese participants said they wanted personal results because it encouraged them to improve their health. Previous studies focused on the dissemination of results to study participants have concentrated on how and when to share results, as well as participant understanding of the results they received [22,41–46]. This is the first study to document specifically how participants anticipate using the study results on their future health behaviors. It also expands on previous research by explaining why sharing study results is important to participants.

The vast majority (84.4%) stated that receiving the results increased their likelihood of participating future research. Study results demonstrate that not only do participants want the results from studies in which they participate, but also that providing those results increases the likelihood they will participate in future research. These findings expand the literature on how sharing study results impacts possible future participation in research. Finally, there was not statically significant variation among participants in the two study arms in their desire to receive both aggregate study results and personal study results and the impact those results would have on their future participation in research.

4.1. Limitations

This qualitative evaluation of participants’ perceptions related to receiving results from a RCT of a culturally adapted Family Model DSME study is not without limitations. First, only Marshallese living in Arkansas were included in the study and findings may not be generalizable to other immigrant or migrant groups. Secondly, only 111 participants were interviewed. While this is a large qualitative sample that allowed us to reach saturation, it may not reflect all the perceptions of all participants. Additionally, findings are from a diabetes intervention and may not be generalizable to all types of future research.

Human subjects approval statement

Study procedures were reviewed and approved by the University of Arkansas for Medical Sciences’ Institutional Review Board (#203482).

Declaration of competing interest

The authors declare that there is no conflicts of interest.

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References

- [1] International Diabetes Federation, *IDF Diabetes Atlas, eighth ed., International Diabetes Federation, Brussels, Belgium, 2017.*
- [2] P. McElfish, B. Rowland, C. Long, et al., Diabetes and hypertension in Marshallese adults: results from faith-based health screenings, *J Racial Ethn Health Disparities* 4 (6) (2017) 1042–1050.

- [3] P. McElfish, C. Long, P. Kohler, et al., Comparative effectiveness and maintenance of diabetes self-management education interventions for Marshallese type 2 diabetes patients: a randomized controlled trial, *Diabetes Care* 42 (2019) 1–9.
- [4] P.A. McElfish, R.S. Purvis, M.K. Esquivel, et al., Diabetes disparities and promising interventions to address diabetes in native Hawaiian and Pacific Islander populations, *Curr. Diabetes Rep.* 19 (5) (2019) 19.
- [5] S. Yamada, A. Dodd, T. Soe, T. Chen, K. Bauman, Diabetes mellitus prevalence in out-patient Marshallese adults on Ebeye Island, Republic of the Marshall Islands, *Hawaii Med. J.* 63 (2) (2004) 45–51.
- [6] N. Palafox, S. Yamada, A. Ou, J. Minami, D. Johnson, A. Katz, *Cancer in Micronesia*, *Pac. Health Dialog* 11 (2) (2004) 78–83.
- [7] L. Hixson, B. Hepler, M. Kim, *The Native Hawaiian and Other Pacific Islander Population 2010*, United States Census Bureau, Washington, DC, 2012.
- [8] P. McElfish, P. Kohler, C. Smith, et al., Community-driven research agenda to reduce health disparities, *Clin Transl Sci* 8 (6) (2015) 690–695.
- [9] P. McElfish, M. Bridges, J. Hudson, et al., Family model of diabetes education with a Pacific Islander community, *Diabetes Educat.* 41 (6) (2015) 706–715.
- [10] P. McElfish, J. Post, B. Rowland, A social ecological and community-engaged perspective for addressing health disparities among Marshallese in Arkansas, *Int J Nurs Clin Pract* 3 (191) (2016) 1–6.
- [11] P. McElfish, J. Hudson, T. Schultz, et al., Developing an interprofessional student-led clinic to address health disparities in a Pacific Islander Migrant Community, *Journal of Student-Run Clinics* 3 (1) (2017) 1–7.
- [12] P.A. McElfish, P.A. Goulden, Z. Bursac, et al., Engagement practices that join scientific methods with community wisdom: designing a patient-centered, randomized control trial with a Pacific Islander community, *Nurs. Inq.* 24 (2) (2017) 1–11.
- [13] P. McElfish, C. Long, B. Rowland, S. Moore, R. Wilmoth, B. Ayers, Improving culturally appropriate care using a community-based participatory approach: evaluation of a multi-component cultural competency training program, Arkansas, 2015–2016, *Prev. Chronic Dis.* 14 (E26) (2017).
- [14] P.A. McElfish, C.R. Long, J.K. Kaholokula, et al., Design of a comparative effectiveness randomized controlled trial testing a faith-based Diabetes Prevention Program (WORD DPP) vs. a Pacific culturally-adapted Diabetes Prevention Program (PILI DPP) for Marshallese in the United States, *Medicine* 97 (19) (2018), e0677.
- [15] P.A. McElfish, R. Moore, M. Laelan, B.L. Ayers, Using CBPR to address health disparities with the Marshallese community in Arkansas, *Ann. Hum. Biol.* 45 (3) (2018) 264–271.
- [16] H. Barker, *Bravo for the Marshallese: Regaining Control in a Post-Nuclear*, in: *Post-colonial World*, Cengage Learning, Belmont, CA, 2012.
- [17] S. Yamada, N. Palafox, On the biopsychosocial model: the example of political economic causes of diabetes in the Marshall Islands, *Fam. Med.* 33 (9) (2001) 702–704.
- [18] K.H.K. Yeary, C.R. Long, Z. Bursac, P.A. McElfish, Design of a randomized controlled comparative effectiveness trial testing a Family Model of Diabetes Self-Management Education (DSME) vs. standard DSME for Marshallese in the United States, *Contemp Clin Trials Commun* 6 (2017) 97–104.
- [19] K.H. Yeary, N. Aitaoto, K. Sparks, et al., Cultural adaptation of diabetes self-management education for Marshallese residing in the United States: lessons learned in curriculum development, *Prog Community Health Partnersh* 11 (3) (2017) 253–261.
- [20] M. Dixon-Woods, C. Jackson, K.C. Windridge, S. Kenyon, Receiving a summary of the results of a trial: qualitative study of participants' views, *BMJ* 332 (7535) (2006) 206–210.
- [21] A.H. Partridge, H.J. Burstein, R.S. Gelman, P.K. Marcom, E.P. Winer, Do patients participating in clinical trials want to know study results? *J. Natl. Cancer Inst.* 95 (6) (2003) 491–492.
- [22] A.H. Partridge, J.S. Wong, K. Knudsen, et al., Offering participants results of a clinical trial: sharing results of a negative study, *Lancet* 365 (9463) (2005) 963–964.
- [23] C.V. Fernandez, J. Gao, C. Strahlendorf, et al., Providing research results to participants: attitudes and needs of adolescents and parents of children with cancer, *J. Clin. Oncol.* 27 (6) (2009) 878–883.
- [24] A. Baylor, C. Muzoora, M. Bwana, et al., Dissemination of research findings to research participants living with HIV in rural Uganda: challenges and rewards, *PLoS Med.* 10 (3) (2013) 4.
- [25] S.B. Trinidad, E.J. Ludman, S. Hopkins, et al., Community dissemination and genetic research: moving beyond results reporting, *Am. J. Med. Genet.* 167 (7) (2015) 1542–1550.
- [26] R. Purvis, T. Abraham, C. Long, M. Stewart, T. Warmack, P. McElfish, Qualitative study of participants' perceptions and preferences regarding research dissemination, *Am. J. Bioeth.* 8 (2) (2017) 69–74.
- [27] C.R. Long, M.K. Stewart, T.V. Cunningham, T.S. Warmack, P.A. McElfish, Health research participants' preferences for receiving research results, *Clin. Trials* 13 (6) (2016) 582–591.
- [28] P.G. Chen, N. Diaz, G. Lucas, M.S. Rosenthal, Dissemination of results in community-based participatory research, *Am. J. Prev. Med.* 39 (4) (2010) 372–378.
- [29] A.H. Partridge, N. Hackett, E. Blood, et al., Oncology physician and nurse practices and attitudes regarding offering clinical trial results to study participants, *J. Natl. Cancer Inst.* 96 (8) (2004) 629–632.
- [30] H. Rigby, C.V. Fernandez, Providing research results to study participants: support versus practice of researchers presenting at the American Society of Hematology annual meeting, *Blood* 106 (4) (2005) 1199–1202.
- [31] C. Long, R. Purvis, E. Flood-Grady, et al., Health researchers' experiences, perceptions, and barriers related to sharing study results with participants, *Health Res. Pol. Syst.* 17 (25) (2019).
- [32] Patient-Centered Outcomes Research Institute, *What we mean by engagement*. <http://www.pcori.org/funding-opportunities/what-we-mean-engagement>, 2018. Accessed October 15, 2018.
- [33] D. Carpenter, V. Nieva, T. Albaghal, J. Sorra, Development of a planning tool to guide research dissemination, in: K. Henriksen, J.B. Battles, E.S. Marks, D.I. Lewin (Eds.), *Advances in Patient Safety: from Research to Implementation (Volume 4: Programs, Tools, and Products)*, Agency for Healthcare Research and Quality, Rockville, MD, 2005, pp. 83–91.
- [34] P. McElfish, R. Purvis, M. Stewart, L. James, K. Yeary, C. Long, Health research funding agencies' policies, recommendations, and tools for dissemination, *Prog. Commun. Health Partnerships: Res. Edu. Action* 12 (4) (2018) 473–482.
- [35] M. Minkler, A. Salvatore, Participatory approaches for study design and analysis in dissemination and implementation research, in: R. Brownson, G. Colditz, E. Proctor (Eds.), *Dissemination and Implementation Research in Health: Translating Science to Practice*, Oxford University Press, New York, NY, 2012, pp. 192–212.
- [36] C.R. Long, M.K. Stewart, P.A. McElfish, Health research participants are not receiving research results: a collaborative solution is needed, *Trials* 18 (1) (2017) 449.
- [37] P.A. McElfish, R.S. Purvis, C.R. Long, Researchers' experiences with and perceptions of returning results to participants: study protocol, *Contemp Clin Trials Commun* 11 (2018) 95–98.
- [38] M.A. Neergaard, F. Olesen, R.S. Andersen, J. Sondergaard, Qualitative description - the poor cousin of health research? *BMC Med. Res. Methodol.* 9 (2009) 52.
- [39] M. Sandelowski, Whatever happened to qualitative description? *Res. Nurs. Health* 23 (4) (2000) 334–340.
- [40] M. Sandelowski, What's in a name? Qualitative description revisited, *Res. Nurs. Health* 33 (1) (2010) 77–84.
- [41] K. Cox, N. Moghaddam, L. Bird, R. Elkan, Feedback of trial results to participants: a survey of clinicians' and patients' attitudes and experiences, *Eur. J. Oncol. Nurs.* 15 (2) (2011) 124–129.
- [42] A. Sarradon-Eck, J. Sakoyan, A. Desclaux, J. Mancini, D. Genre, C. Julian-Reyniey, They should take time": disclosure of clinical trial results as part of a social relationship, *Soc. Sci. Med.* 75 (2012) 873–882.
- [43] K. Clift, C. Halverson, A. Fiksdal, A. Kumbamu, R. Sharp, J. McCormick, Patients' views on incidental findings from clinical exome sequencing, *App. Trans. Genomics.* 4 (2015) 38–43.
- [44] D.I. Shalowitz, F.G. Miller, Disclosing individual results of clinical research: implications of respect for participants, *Jama* 294 (6) (2005) 737–740.
- [45] A.H. Partridge, E.P. Winer, Informing clinical trial participants about study results, *J. Am. Med. Assoc.* 288 (3) (2002) 363–365.
- [46] D.I. Shalowitz, F.G. Miller, Communicating the results of clinical research to participants: attitudes, practices, and future directions, *PLoS Med.* 5 (5) (2008), e91.