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Engaging Youth Advocates in Community Based Participatory Research on Child Farmworker Health in North Carolina

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Abstract

Background: Wake Forest School of Medicine (WFSM) investigators and Student Action with Farmworkers' (SAF) *Levante* Leadership Institute, a farmworker youth program, are collaborating on a Community Based Participatory Research (CBPR) study.

Objectives: (1) Describe the collaborative process between WFSM investigators and the *Levante* advisory board during the strategic planning and implementation phase and (2) highlight practices that support the collaboration and project success.

Methods: The longitudinal Hired Child Farmworker Study examines the health and safety of hired Latino child farmworkers in North Carolina. Two *Levante* alumni co-investigators lead research-related activities with the *Levante* advisory board.

Lessons Learned: Challenges to CBPR with youth are overcome by the longstanding partnership between WFSM and SAF, attention to logistical details, power sharing, building on shared values, and assessment of youth preferences.

Conclusions: The partnership between WFSM and *Levante* demonstrates the mutual benefit of CBPR and will continue during the upcoming study phases.

Background

Study context

Agriculture is an extremely hazardous industry in the US. Children as young as 10 years of age can be hired to do farm work as long as those under 14 years of age have parental consent.^{1, 2} Injuries and illness rates among child agricultural workers are high, with reports indicating that a child dies in an agriculture-related incident every 3 days.^{3, 4} Little research has examined health among children engaged in hired farm work. In North Carolina (NC), children work in crops including tobacco, blueberries, sweet potatoes, and tomatoes. Many of these children are part of the marginalized Latino farmworker community.

In the past 25 years, some academic investigators have emphasized the importance of community members' perspectives in planning and implementing research studies. Community Based Participatory Research (CBPR) is an approach to scientific inquiry that embraces the value of equitable collaboration with community members in the research process.^{5, 6} Several researchers have conducted CBPR with adult farmworkers,^{7–11} but few have conducted research involving youth farmworkers. Harley and colleagues have successfully incorporated Latino youth in an advisory and researcher capacity for environmental health projects.^{12–15} The Hired Child Farmworker Study differs from other studies by partnering academic investigators and youth with farm work experience.

Project history

The Hired Child Farmworker Study was developed based on recommendations from state agencies and community organizations suggesting the need for empirical studies examining the health effects of doing farm work at a young age. In 2012, Wake Forest School of Medicine (WFSM) and East Carolina University (ECU) investigators partnered with the North Carolina Justice Center, NC FIELD, and Student Action with Farmworkers (SAF) to conduct a pilot study of the occupational health and safety of hired Latino child farmworkers. The pilot study team interviewed 87 children aged 10–17 about their work experiences.^{3, 16, 17} The pilot study led to the development of the larger Hired Child Farmworker Study, the focus of this manuscript.

Incorporating youth perspectives in CBPR

The CBPR model for the Hired Child Farmworker Study incorporates community participation in four domains: (1) consultation—delineating what should be done; (2) strategic planning—deciding how it should be done; (3) implementation—completing the actual tasks; and (4) dissemination—sharing what was accomplished with the community and policy makers.^{11, 18, 19} While the overall project includes several modes of community participation (e.g., a professional advisory committee, community field interviewers, and involvement of many NC organizations), this paper focuses on the nature of youth engagement, particularly during the strategic planning and implementation phases of the project (see figures 1 and 2).

Objectives

This paper reflects on the CPBR process involving farmworker youth in eastern NC by (1) describing the CBPR process between WFSM researchers and SAF *Levante* co-investigators and members and (2) highlighting key lessons learned that support the collaboration and project success.

Methods

The Hired Child Farmworker Study is a 5-year mixed-methods project with qualitative formative research followed by a repeated measures survey. Inclusion criteria for the repeated measures survey are: 1) ages 10–17, 2) working in farm work in the 3 months prior to recruitment, 3) self-identifying as Hispanic or Latino, and 4) fluency in English or

Spanish. Signed parental permission and signed youth assent were obtained for each enrolled participant. All procedures were approved by WFSM Institutional Review Board.

The primary community partner for youth involvement in an advisory and co-investigator capacity is SAF, a non-profit organization focused on farmworker justice through advocacy and education based in Durham, NC. One of SAF's programs is the *Levante* (to raise up) Leadership Institute, an academic year-program for 10–15 Eastern NC farmworker high school students and their parents focusing on social justice, health, and educational approaches such as popular education and cultural arts. These approaches are oriented toward social change and emphasize collaboration in a peer-to-peer learning environment; they lead youth to critically assess issues in their community, and include pedagogical tools such as theater, games, and other expressive forms to foster collective action.^{20, 21} Over the past 20 years, SAF staff members have been collaborators serving as co-investigators, interns, sub-grantees, and advisory board members on a variety of WFSM CBPR studies related to pesticide exposure and other health issues among adult farmworkers and their families,^{22, 23} health communication,^{24, 25} and farmworker housing.^{26–28} The Hired Child Farmworker Study builds on this existing institutional relationship, as SAF's Executive Director and *Levante* director are co-investigators. SAF helped in the development of, and has a subcontract on, this grant-funded project.

The *Levante* advisory board for the Hired Child Farmworker Study is comprised of two *Levante* alumni (third and fourth authors of manuscript), who are paid co-investigators (hereafter: *Levante* co-investigators), and the 10–15 members of *Levante* (hereafter: *Levante* members). Members of the *Levante* advisory board are ineligible for inclusion as study participants because they are involved in the design and implementation of the study. *Levante* co-investigators are liaisons between WFSM academic investigators and *Levante* members and meet with WFSM project manager (first author) and SAF *Levante* director (second author) to provide feedback on the project, and to plan and lead activities during *Levante* retreats and day-long meetings. An average of ten youth attend each meeting and their ages range from 13–18 years.

Youth CBPR Process

This manuscript focuses on the first completed academic year of the Hired Child Farmworker Study, which builds on the strong relationship between WFSM academic investigators, SAF staff, and the *Levante* co-investigators and members. In the first year, youth devoted time to the research project at their meetings, and WFSM project manager and *Levante* director allocated staff time to facilitate the interactions.

Levante co-investigator collaboration

Alumni of *Levante* (high school graduates who are beginning college) have the opportunity to apply for two renewable youth co-investigator positions. These *Levante* co-investigators receive a stipend (approximately \$500 per semester) and provide leadership in the project with *Levante* members. The WFSM project manager and *Levante* director communicate with *Levante* co-investigators regularly with project-related questions and for participant recruitment assistance, and invite them to participate in professional advisory committee

meetings. Additionally, *Levante* co-investigators complete a research orientation and training in the protection of human research subjects. Prior to each *Levante* gathering, WFSM project manager and SAF *Levante* director meet with *Levante* co-investigators to plan and coordinate leadership roles for activities with *Levante* members. This provides *Levante* co-investigators opportunities to implement skills they acquired from the *Levante* program. In September 2017, *Levante* co-investigators, *Levante* director and WFSM project manager presented a poster at the “Advancing the Science of Community Engaged Research Conference” in Washington, DC.²⁹ *Levante* co-investigators helped prepare this manuscript for publication.

Levante member collaboration

SAF recruits *Levante* members in local high schools and through peer referrals. The program structure includes multiple meetings (three overnight retreats and five day-long meetings) during the academic year for *Levante* members and parents. The program covers college preparation, social justice, and life skills through racial, gender, and economic justice trainings, themed workshops, cultural arts, and parent-involvement meetings. Members receive a \$1000 yearly scholarship for their participation in the *Levante* program. The CBPR component of the Hired Child Farmworker Study is embedded within the *Levante* program framework and four meetings included sessions devoted to study collaboration (see table 1).

In the first overnight retreat of the 2016–2017 academic year, the WFSM project manager oriented *Levante* to the study and discussed research to inform policy. *Levante* co-investigators led a group discussion with the *Levante* members on the importance of research, and elicited feedback on research topics that are important to their peers and best strategies to maintain contact with youth study participants, including information about most popular social media platforms and most effective ways to communicate with youth. WFSM investigators and *Levante* co-investigators used the feedback to prepare for upcoming data collection and for the participant retention strategy. For example, *Levante* members emphasized the importance of making frequent calls and home visits to participants and building relationships with their families. They stressed the need to build trust, highlighting the heightened fear in their communities due to increased anti-immigrant rhetoric surrounding the 2016 election. WFSM investigators used these insights in selecting and training community field interviewers.

At the second day-long retreat of the same academic year, *Levante* co-investigators edited the draft questionnaire and provided input on specific questions and terminology. *Levante* members were particularly helpful in effectively phrasing survey questions. Feedback was successfully elicited by using an interactive popular education game that consists of reading aloud questions and discussing answers in a group. For this game, *Levante* members discussed draft survey questions and other WFSM investigator queries. One example the group discussed was “do youth refer to their direct supervisor in the fields as *el patron*, *el jefe*, or *el contratista*?” Youth identified the variability of uses for these terms, which increased precision in the final questionnaire. The game made the session hands-on, while

acknowledging that youth are sources of valuable knowledge.³⁰ Importantly, one of the *Levante* co-investigators suggested this method of eliciting feedback from the group.

During the third overnight retreat, WFSM project staff pilot-tested the English and Spanish versions of the survey with *Levante* members. After piloting the survey, WFSM staff solicited feedback with members individually. Youth who participated received \$20. Outcomes for this portion were two-fold: 1) WFSM received valuable feedback on survey questions, organization, and time frame; and 2) *Levante* members gained deeper insight into survey content and purpose, in addition to monetary compensation.

The fourth day-long meeting included a farmworker clinic visit with the *Levante* advisory board, led by the WFSM project manager. At the clinic, the project manager conducted an occupational safety and health workshop. Then youth participated in group data analysis with excerpts from in-depth interviews from the project related to occupational injuries. The analysis activity generated meaningful discussion about the connections between occupational health and the social context for farmworker youths' lives.

Key lessons learned: Practices that support collaboration and project success

Reflecting on the strategic planning and implementation phases of this project, we highlight key lessons learned about practices that have facilitated meaningful youth engagement involving the structure of partnerships, power-sharing practices, shared values, and evaluation of youth preferences.

Deepening a longstanding relationship

The longstanding and continued relationship between WFSM and SAF is key for collaboration and project success. First, the longstanding nature of the collaboration maintains a channel for incorporating youth as they rotate through *Levante*. Youth transitioning out of youth-led programs is a barrier often encountered in community-partnered research with youth.³¹ The team has adapted to this challenge by absorbing some graduating *Levante* youth into SAF's academic-year internship program for college students, which maintains consistency, provides continued institutional structure for collaboration, and reduces the time burden on project staff of re-orienting youth partners. Second, WFSM and SAF have demonstrated long-term commitment to the collaboration through multiple projects since 1996 and have made significant institutional commitments to the partnership. In this project, the commitments include significant WFSM project manager and *Levante* director staff time for mentoring *Levante* co-investigators and interfacing with *Levante* members. Finally, the youth-focused³¹ CBPR aspect of this project features youth in the *Levante* advisory board who are representative of the research population of the study. In prior CBPR collaborations between WFSM and youth, the students were not necessarily representative of study population, as some were graduate students or college students working on the project for course credit.³² This shift extends the team's previous collaborative work.

Attention to logistical details and mutual benefit

Attention to logistical details also supports project success. For example, *Levante* co-investigators have frequent contact with the project manager and *Levante* director in a setting familiar to co-investigators (library, coffee shop, their church space). These informal interactions facilitate rapport building among the team members that enhances the effort to take seriously co-investigators' concerns, advice, and ideas.

Levante programmatic activities (overnight retreats, day-long meetings) ensure structure for on-going youth participation. Having WFSM researchers attend these scheduled events, rather than creating new meetings, reduces time and transportation burdens on youth. In addition, the thematic overlap between *Levante* programming and the study (both focus on health and the well-being of child farmworkers) allows the integration of research project work into *Levante* retreats in a seamless way. However, the structure also presents competition for inclusion on the meeting agenda. Furthermore, the time limitations of research workshops present a barrier to rapport building between the WFSM project manager and the *Levante* members. To overcome this barrier, the WFSM project manager attended as many meetings as possible, even if the agenda did not include research specific activities.

Power-sharing practices

Power-sharing is a critical part of CBPR.³³ CBPR with youth presents challenges to power-sharing between youth and adults, yet evidence suggests that power-sharing increases youth engagement and participation in research projects.³¹ Studies on youth engagement indicate that fully engaging youth and building youth capacity require careful attention to participation barriers, including lack of time and resources, and failure to properly orient youth partners.^{33, 34} The Hired Child Farmworker Study addresses these obstacles directly.

This project provides monetary compensation for youth co-investigators who lead the *Levante* advisory board, and for youth from the advisory board who piloted the survey. This has encouraged participation, and addressed power dynamics and power-sharing³⁵ in the collaboration. Issues of compensation in CBPR are challenging³³ but compensation may increase youth's feelings of equity, value, and investment in a project. In end-of-year surveys, *Levante* members indicated the benefit of monetary compensation for the time they dedicated to the project.

Additionally, the youth in this project are engaged in all phases of the research process and co-investigators take leadership roles in facilitating activities. While many CBPR projects with youth have primarily engaged them in the formative research phase (e.g., designing survey instruments) or data collection,³⁶ *Levante* co-investigators and members in this project are also involved in interpreting results and will be involved in disseminating results. This is uncommon for CBPR projects involving youth,³⁵ and the approach has benefitted the research project while also conferring benefits to youth. The youth co-investigator feature might represent a larger benefit for individual *Levante* co-investigators, including plausible health benefits of civic engagement.³⁷ Through their involvement, *Levante* co-investigators receive significant staff attention from the WFSM project manager and *Levante* director

including academic mentorship and serving as professional references, engage with the research study process at a high level,³³ gain access to a network of statewide professionals and agencies, and develop research skills and exposure to career options.

Another aspect of power-sharing involves building rapport and trust between the WFSM project manager and the *Levante* members. During initial formal meetings, *Levante* members were uninterested in the technical aspects of the research study, and were reticent in their participation. Replacing some structured interactions between the *Levante* members and the project manager with informal interactions (e.g., playing soccer, attending SAF events) increased rapport between the project manager and youth. Furthermore, shifting the balance of decision-making about time spent together, increased youth participation during structured, research-specific sessions.

Building on shared values

The considerable methodological and thematic overlap between the design of the research study and the design of the *Levante* program supports the success of the youth-based CBPR component of this project. The research study and *Levante* program share values of using a collaborative approach to achieve health equity for marginalized farmworker communities. The *Levante* program uses participatory approaches, such as popular education, to determine the content of the research study workshops. In turn, *Levante* members incorporate what they learn about popular education into developing educational resources to disseminate study results to farmworker communities. The programmatic structure and thematic and methodological overlap have facilitated consistent youth involvement and insertion of *Levante* advisory board responsibilities into *Levante* programming.

Assessment of youth preferences

Assessing the experience of youth in this project through ongoing individual conversations and end-of-year evaluations is key to success. For example, *Levante* members indicated that they prefer receiving updates from and providing consultation to WFSM through interactive activities rather than presentations and lectures. Through these activities, *Levante* members are able to make connections between the role of empirical evidence and research in advocating for policy change and the importance of tailoring information to a given audience for maximum impact. *Levante* members stated that they value the educational and professional development opportunities acquired through participation in occupational health and research methods workshops. They indicated that they draw connections between topics of popular education and farmworker advocacy and the importance of community participation in research.

Conclusion

This paper describes the CBPR process of engaging youth in an advisory and co-investigator capacity in the early phases of a multi-year research study examining the health and safety of hired Latino child farmworkers in NC. In 2018–2020, the *Levante* advisory board will continue to evaluate study data, learn about research through workshops and hands-on activities, participate in data collection, provide feedback on policy briefs²⁵ and tour WFSM

to learn about medical careers. The final year of the study will focus on developing arts-and theater-based educational resources to disseminate study results.

The CBPR process between WFSM and the *Levante* advisory board in the early phases of the Hired Child Farmworker Study is mutually beneficial. Drawing on *Levante* advisory board knowledge, who share similar identities and lived experiences with the study sample, has provided WFSM academic investigators with valuable insights into how to approach survey content, participant retention, and future aspects of the study. Members of the *Levante* advisory board acknowledged the benefit of learning about research that is relevant to their social milieu and of gaining access to academic investigators for mentorship.

Factors that have facilitated this process and overcome some of the challenges inherent in CBPR projects include the longstanding nature of the collaboration and partnership between WFSM and SAF, attention to logistical details and mutual benefit, power sharing practices, building on shared values, and assessing youth preferences. This project demonstrates the possibilities for enhancing community participation, specifically that of marginalized and under-represented youth, to strengthen scientific studies while building local capacity to foster positive social change.

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Figure 1.
Organizational structure of research team (2016–2017).

Figure 2.
Hired Child Farmworker Study timeline and methods (2016–2020).

Table 1.WFSM and SAF *Levante* Leadership Institute 2016–2017 academic year collaboration

<i>Levante</i> programming	Research study activities
Overnight retreat (September 2016)	1) Orientation to child farmworker study ^{1,2} 2) Group discussion with <i>Levante</i> members on retention and communication strategies with study participants ³
Day-long meeting (December 2016)	1) <i>Levante</i> co-investigators edit survey draft ³ 2) Game to elicit feedback on survey terms with <i>Levante</i> members ³
Overnight retreat (January 2017)	1) Pilot testing survey draft with <i>Levante</i> members ¹
Day-long meeting (April 2017)	1) Farmworker clinic visit ^{1,2} 2) Occupational Safety and Health workshop ¹ 3) Group data analysis of in-depth interview excerpts ^{1,2,3}

Research study activity leaders

¹WFSM project manager²*Levante* director³*Levante* co-investigators