Building Sustainable Organizational and Community Capacity for Research Partnerships: A Decade of Experience

Al Castro, Sarah Esmond, Shary Perez, Caitlin Scott, Tyson Jackson, Susan Racine Passmore

Progress in Community Health Partnerships: Research, Education, and Action, Volume 15, Issue 4, Winter 2021, pp. 553-560 (Article)

Published by Johns Hopkins University Press
DOI: *https://doi.org/10.1353/cpr.2021.0045*

Building Sustainable Organizational and Community Capacity for Research Partnerships: A Decade of Experience

Al Castro[1], Sarah Esmond, MS[2], Shary Perez[1], Caitlin Scott[2], Tyson Jackson[2], and Susan Racine Passmore, PhD[2]

(1) United Community Center/Centro de la Comunidad Unida; and (2) Collaborative Center for Health Equity, School of Medicine and Public Health, University of Wisconsin- Madison

Submitted 12 June 2020, revised 24 March 2021, accepted 8 June 2021.

Abstract

The purpose of this article is to share community partner perspectives of impact and lessons learned from a decade long community-academic partnership between the Collaborative Center for Health Equity at the University of Wisconsin-Madison, and the United Community Center/Centro de la Comunidad Unida, a nonprofit community-based organization providing services across the lifespan for Latino communities of Milwaukee. The partnership was established in 2010 to support bidirectional communication, trust building and mutual benefit though community engaged research and collaborative student teaching. Over the years, we have achieved a variety of outcomes on both sides of the partnership. For our community organization, the partnership has evolved to create substantial benefits through opportunities for new collaborations, service program development and grantsmanship. Several factors contributed to our success including sustained stable funding not tied to an individual research project and academic investment in community capacity.

Keywords

Community health partnerships, health disparities, community health research, health promotion, power sharing, community engagement, Latinos

Milwaukee is home to 40% of all Latinos in Wisconsin, a community that has rapidly grown during the past few decades.[1] Over this time, we faced many challenges including economic disadvantage, anti-immigration sentiment and policies, and health inequities.[1–4] The United Community Center/Centro de la Comunidad Unida (UCC) was established in 1970 as a trusted community resource. In those days it was a small neighborhood center. Today UCC is a large, well-established non-profit community organization of over 400 employees serving 18,000 residents of Milwaukee County through a wide range of programs in education, early childhood development, youth services, elderly services, cultural arts, recreation, community development, and health and human services across the life span. We owe our success to many things, including a strong community and exceptionally hard-working staff. UCC and its programs have also benefitted from a vibrant, long-standing community-academic partnership with the University of Wisconsin-Madison (UW), Collaborative Center for Health Equity (CCHE). This partnership was established with the shared goals of increasing Latino representation in research and increasing research on topics of interest and direct applicability to the Latino community. The positive impact of community partnership on academic health centers is well documented from the researcher perspective.[5–7] Less often presented are longer-term benefits for the community partner. We reflect here on what our decade long partnership has meant to our growth as a community-based organization (CBO).

A PARTNERSHIP FORMS

The partnership began in response to interest on both sides in late 2009. The UCC leadership recognized the potential to harness academic research to strengthen effectiveness of service provision, thus, our Director approached the Dean of the UW-Madison School of Medicine and Public Health. At the same time, the Wisconsin Prevention of Obesity and Diabetes group (WI POD), an interdisciplinary network of physician researchers at UW-Madison, had a project in need of community partners. Lacking experience in community engagement, WI POD relied on support from the CCHE, a then newly designated Center of Excellence in Minority Health and Health Disparities Research by the National Institute on Minority Health and Health Disparities Research (NIMHD P60MD003428).[5–7] CCHE brokered an agreement which established the first UCC/CCHE "Research Ambassador" (RA), supported as a UCC employee, to facilitate the WI POD Healthy Alternatives Partnership Program for Youth (HAPPY) program.

In our partnership, there was a strong emphasis on sustainability from the beginning. Like many CBO's, UCC was interested in a long-term commitment. CCHE was prepared for such a relationship, since its leadership had extensive experience in community engagement, and support from the CCHE Center of Excellence award.[5,7] As such, the agreement did not directly tie the RA position or the relationship to the HAPPY project. To demonstrate trustworthiness and preserve UCC's autonomy, CCHE instead proposed a full-time RA position embedded within UCC. The position was financially supported by CCHE, but the person was hired and employed directly by UCC. This structure positioned the RA as part of UCC from the beginning and, as such, the RA understood our priorities and organizational culture. With UCC's autonomy over who was in the RA position, research became part of our mission rather than "added on" work.

Many factors were critical to success of the initial community-academic partnership such as the first person employed in the RA position. Initially, UCC staff were skeptical about working with researchers. Some doubted a group of largely white academics would have anything of value to offer to their work in the community. Others felt protective of their clients, especially the more vulnerable children and the elderly. The first RA, a fully bilingual Latina with a Master of Public Health degree, was both passionate about community-based health research and the Latino community served by UCC. Her efforts to maximize communication early on influenced success of the partnership. For example, she scheduled extra time after meetings with researchers to hold informal "town hall" sessions to answer questions from staff and explore potential problems in communication and workflow. Any problems were caught early and resolved with the research team. This process provided a guided transition that helped allay staff anxiety while maintaining quality of service provided to clients.

Over time, the staff began to see how research could benefit their clients. For example, in 2012, staff in the UCC Memory Clinic observed the magnitude of stress experienced by family caregivers and lack of culturally appropriate services to support them. Academic partners helped us create and get funding for a two-year pilot project to fill the gap. *Cuidadores Latino Unidos* was an adaptation of an evidence-based support program originally developed for Caucasian family caregivers.[8] We adapted that model into a pilot intervention for the Latino culture, trained our bachelor level bilingual social workers to deliver the program, building our internal capacity, and saw significant reductions in depression and increases in feelings of social connectedness. A manuscript is being written on this project. In time, success of this project led to development of a Milwaukee based Latino Consortium led by UCC and, supported by the local Alzheimer's Association, other community partners and academic representatives. This consortium eventually leveraged a new five year grant in 2018 from the United States Department of Health and Human Services, Administration on Community Living ($980,000) to expand our ability to serve our families impacted by dementia through earlier detection of dementia, a mobile memory clinic and expanded services for our Latino families.

We also learned from mistakes along with our academic partners. For example, in one project, a research team approached us to test a diabetes intervention with a Latino population. This team came to us with everything in place, including the intervention that was developed and tested with a different ethnic population, data collection methods and recruitment procedures. UCC staff were asked to assist with access to the target population and did not have much opportunity to provide feedback on the intervention or

methodology. Unfortunately, the project's initial recruitment and enrollment efforts, which relied almost entirely on research staff from outside our community, fell flat at UCC. Our clients did not respond well to the group recruitment method and group consenting process. They were confused by complicated eligibility requirements and experienced difficulties communicating their questions or problems to the research staff. After feedback from our staff, the research team modified its approach, involved the RA more directly and experienced greater success.

We have since learned to avoid these types of "plug and play" approaches. We now know that we work best with researchers who come to us with flexible ideas and an authentic commitment to incorporating our thoughts and perspectives in the co-design of projects. We also learned that having effective and frequent communication with principal investigators and research staff can help resolve conflicts caused by differences in the priorities of "science" versus service delivery. In early days, we struggled with long informed consent documents, inflexible eligibility requirements, exclusion of individuals with similar needs from "intervention" groups and other issues that range from annoyances to significant emotional and ethical dilemmas for our staff. We have learned to say "no" to researchers and projects that do not meet our needs, and insist on equitable involvement of UCC staff and/or the community in project planning and delivery.

Over the years, our infrastructure also grew. UCC developed and expanded infrastructure to accommodate interest from other researchers and build capacity for community-engaged research. We evolved from lack of organization around research activities before 2010 to establishment of the RA position embedded in the Human Services unit, resulting in an independent Health Research Program. Today the Health Research Program is staffed by a Director, RA and interns who work together to vet new or pending research proposals from universities in a structured "one-door in" approach. A structured decision-making process is also now in place to guide this process, with approval from executive leadership. (See Appendix 1: UCC Health Research Program Infrastructure materials.)

Since 2010, seven UCC employees have filled the role of RA. They have worked on many federally and locally funded research projects addressing topics such as obesity prevention, Alzheimer's disease, precision medicine, mental health, chronic disease management, cancer, and falls prevention. For all of these projects, RAs served as an initial "sounding board" for new researchers coming to Milwaukee to plan their project concepts. We provide advice and consultations to create effective and culturally appropriate approaches. The RAs are first to assess appropriateness of a proposed project and weigh in on our available internal bandwidth to support it. If they deem it acceptable, the Health Research Program often assists with hosting preliminary focus groups to increase community and participant voice in the design and implementation of the research. RAs continue to provide guidance and consultation to researchers as the project moves along and assist with dissemination activities as needed.

By not tying the partnership to a single project, we were able to explore new ways to collaborate over the years. For example, RAs have played a role in the professional development of UW-Madison medical students, faculty and scholars through numerous training programs. The most impactful of these have been the CCHE's Health Equity Leadership Institute and the School of Medicine Public Health's Training in Urban Medicine and Public Health (TRIUMPH) programs. Since 2012, UCC staff have served on the Health Equity Leadership Institute faculty for eight nationally representative cohorts of early stage scholar investigators.[9] In TRIUMPH, RAs sit on the community advisory board and serve as liaison and mentor for students in community medicine.[10] UCC has been the site of several TRIUMPH student projects and the RAs have helped many students transform community priorities and needs into suitable projects.

ORGANIZATIONAL AND COMMUNITY BENEFITS

There have been many benefits to UCC and the Latino community of Milwaukee over our decade in partnership with CCHE. As noted, UCC has been able to leverage research capacity and create new and effective service activities such as our work to support families impacted by dementia. In addition, the program empowered RAs at UCC to better inform and educate other UCC staff and program leaders about health inequities and the use of "science" to better understand how to serve our clients.[11–15] For example, while we were aware that diabetes and obesity were problems for the Latino community, researchers helped us see the problem

in greater detail in our specific client community and helped us design and test new interventions. The original HAPPY project found 30% of children in the UCC-run charter school were obese and helped us institute programming to prevent childhood obesity through school-based youth nutrition and fitness programs.[16–20] Similarly, a TRUIMPH student helped us by implementing a diabetes assessment in our school and elderly programs. She found both high rates of diabetes as well as low levels of active diabetes management which led to new programs to address diabetes across the lifespan. These include the *Salud de la Mujer* project, which developed and used Spanish photobooks (fotonovelas) and a community-driven and locally created Spanish soap opera (*Dulce Tentacion*) to effectively educate and communicate with the Latino community about diabetes.[14] We have also been on the "ground floor" of other new interventions for Latinos such as *Cuiadadores Latino Unidos* (described elsewhere in this article) and *Pisando Fuerte,* a Spanish language and cultural adaptation of *Stepping On*, and an evidence-based falls prevention program. This program will soon be available for older clients and our staff are the first Spanish speaking facilitators.[11]

Our partnerships have been an asset to our work in direct service delivery. As CBOs evolve and their funding sources and target groups develop and change, we often encounter expectations from funders and the community for measuring outcomes and change rather than counting raw numbers of persons served or activities provided. Many funding sources now require more use of evidence-based interventions and processes. These expectations can pose a challenge to CBOs not familiar with evidence-based interventions, data collection, valid outcome measurements, and other such concepts. Collaboration is key to effectively fulfill contract requirements from funders and remain competitive as a service provider. Our Health Research Department has been vital to our ability to demonstrate evaluation capacity when applying for and managing grants. In fact, a previous RA has gone on from that position to become the internal evaluator of a large award from the Substance Abuse and Mental Health Services Administration. Since 2010, via the RA and its health research programs, UCC has been able to leverage about $2.4 million in new research or program improvement funding for the organization (see Appendix 2: UCC Funding History).

The UCC/CCHE partnership benefitted the wider Latino community in Milwaukee in other ways as well. Over the years, RAs have built credibility with other community partners and organizations. We have been able to "spread the wealth" so UCC does not have a monopoly over the voice of the Latino community. RAs have been called upon to consult on outreach strategies to involve other Latino serving organizations in the UW-Madison's statewide health survey, Survey on the Health of Wisconsin, and the National Institutes of Health (NIH), *All of Us* project, a component of the nationwide NIH Precision Medicine Initiative. RAs now reach out to other Latino CBOs and coalitions. The Program Director of the Health Research Department's involvement with the Milwaukee Latino Health Coalition led to formation of a new Research Action Committee which he chairs. The current RA serves on advisory committees for several research projects involving other CBOs and universities. As members of the Latino Aging Consortium in Milwaukee, we have worked to ensure research activities are included in its structured mission to address chronic aging issues among Latino older adults.

Finally, our partnership has created opportunities for professional development. Over the years, RAs at UCC have used the experience as a springboard for their careers. For example, two previous RAs moved into research positions at local private and state universities, another is enrolled in a PhD program at the University of California-Davis and a third advanced to UCC management role in quality assurance. UCC staff are published co-authors through their work with UW-Madison researchers and others.[11–13,18,21] We have also collaborated with other universities to increase the pipeline of future health professionals through programs to engage undergraduate Latino students at local universities.

CONCLUSION

Both sides of our community-academic relationship have benefitted during our 10 years together. We encourage other CBOs to consider our model and similar types of research collaborations. The concept of a community-academic research partnership may be unfamiliar to many CBOs either due to the character, mission and structure of the organization or upon reflection of immediate priorities of the target population served. Grassroots single-service organizations, particularly, may not see research as part of their mission or capacity. Their

drive and energy are focused on providing direct services to their community and they may view research as intrusive, complicated, and time intensive. This is understandable and it is how many of us saw it in the beginning.

However, involvement in community engaged research provides opportunities to learn how to use "science" to get a better handle on how to create effective programs and build new directions to grow. Research provides opportunities to highlight health disparities in our communities to key stakeholders and facilitates a direct voice in how researchers plan and conduct health disparity studies, while being treated as equals with valued expertise to offer.

Finding the "right" academic partner is key. Larger scale grants, such as the NIH Centers of Excellence awards, can be opportunities to provide a base of stability to build partnerships that thrive.[5,7] Our advice would be to resist relationships that appear limited to a single, one-and-done research project. These can feel more like "vendor/purchaser" relationships rather than long term investments. Once that type of project ends there is no financial or structural support to maintain a partnership and growth may not be consistent or advanced for either the community or academic partner. Our experience tells us the real benefit is found over time. Our partners at CCHE agree the foundation of our relationship in the RA position and 10 years of stability have been critical to the breadth and depth of what we have achieved together. For UCC, the community academic partnership has been critical to our growth from a small agency to a large, established and mature CBO now focused on making systemic changes to improve the wellbeing of the community.

ACKNOWLEDGMENTS

The authors thank all of those who have filled the position of the UCC/CCHE RA over the years in addition to our authors Al Castro and Shary Perez. They are Angelica Rendon Delgado, Magdalisse Henderson, Marcia Villa Walton, Militza Bonet Vazquez, and Mirtha Sosa Pacheco. We would also like to note that the creation of our partnership was supported by a Center of Excellence award from the National Institute for Minority Health and Health Disparities (P60MD003428). CCHE is currently supported by the UW Institute for Clinical and Translational Research, a Clinical and Translational Science Award (CTSA), from the NIH National Center for Advancing Translational Sciences (NCATS) (UL1TR002373). The content is solely the responsibility of the authors and does not necessarily represent the official views of funders.

REFERENCES

1. Levine, Mark. Latino Milwaukee: A Statistical Portrait. University of Wisconsin-Milwaukee, Center for Economic Development [updated 2016]. Available from: https://www.greatermilwaukeefoundation.org/files/7914/6215/2972/Latino_Milwaukee_Study_2016.pdf
2. Healthiest Wisconsin 2020 Baseline and Health Disparities Report. Healthiest Wisconsin 2020 Baseline and Health Disparities Report; 2014. Wisconsin Department of Health Services.
3. Wisconsin Collaborative for Healthcare Quality and the University of Wisconsin Health Innovation Program. Wisconsin Health Disparities Report; 2019. Wisconsin Collaborative for Healthcare Quality.
4. Ismay J. Victim of Milwaukee acid attack says he was told to 'go back to your country.' The New York Times [updated 2019 Nov 4; cited 2020 May 1]. Available from: https://www.nytimes.com/2019/11/04/us/milwaukee-acid-attack-victim.html
5. Standifer, MPH M, Julie Baldwin P, Jenna Davis MPH, et al. A transdisciplinary approach to eliminate cancer disparities: An overview of community engagement and outreach efforts in a National Institute of Health Center for Excellence. J Health Disparities Res Pract. 2014;7(2).
6. Walsh M, Rivers D, Pinzon M, Entrekin N, Hite E, Baldwin J. Assessment of the perceived role and function of a community advisory board in a NIH Center of Excellence: Lessons learned. J Health Disparities Res Pract. 2015;8(3).
7. Hatfield PM, Sorkness CA, Esmond SL, Adams AK. Achievements in health equity: Nesting an NIMHD Center of Excellence within a CTSA. Clin Transl Sci. 2015;8(1):5–7.
8. Mittelman MS, Roth DL, Haley WE, Zarit SH. Effects of a caregiver intervention on negative caregiver appraisals of behavior problems in patients with Alzheimer's disease: Results of a randomized trial. J Gerontol Ser B. 2004;59(1):P27–P34.
9. Butler J, Fryer CS, Ward E, et al. The Health Equity Leadership Institute (HELI): Developing workforce capacity for health disparities research. J Clin Transl Sci. 2017;1(3):153–9.
10. Haq C, Stearns M, Brill J, et al. Training in urban medicine and public health: TRIUMPH. Acad Med. 2013;88(3):352–63.
11. Mora Pinzon M, Myers S, Jacobs EA, et al. "Pisando Fuerte": An evidence-based falls prevention program for Hispanic/Latinos older adults: results of an implementation trial. BMC Geriatr. 2019;19(1):258.
12. Hanlin ER, Delgado-Rendón A, Lerner EB, Hargarten S, Farías R. Fall risk and prevention needs assessment in an older adult Latino population: A model community global health partnership. Prog Community Health Partnersh. 2013;7(2):191–9.

13. DeNomie M, Medić V, Castro A, Vazquez MB, Rodriguez B, Kim J. Lessons learned from a community–academic project using telemedicine for eye screening among urban Latinos. Prog Community Health Partnersh. 2019;13(2):183–9.

14. Hinojosa MS, Nelson D, Hinojosa R, et al. Using Fotonovelas to promote healthy eating in a Latino community. Am J Public Health. 2011;101(2):258–9.

15. Gerdes AC, Kapke TL, Grace M, Castro A. Feasibility, acceptability, and preliminary outcomes of a culturally adapted evidence-based treatment for Latino youth with ADHD. J Atten Disord. Published online 2019:1087054718821729.

16. Santiago-Torres M, Adams AK, Carrel AL, LaRowe TL, Schoeller DA. Home food availability, parental dietary intake, and familial eating habits influence the diet quality of urban Hispanic children. Child Obes. 2014;10(5):408–15.

17. Santiago-Torres M, Cui Y, Adams AK, et al. Structural equation modeling of the associations between the home environment and obesity-related cardiovascular fitness and insulin resistance among Hispanic children. Appetite. 2016;101:23–30.

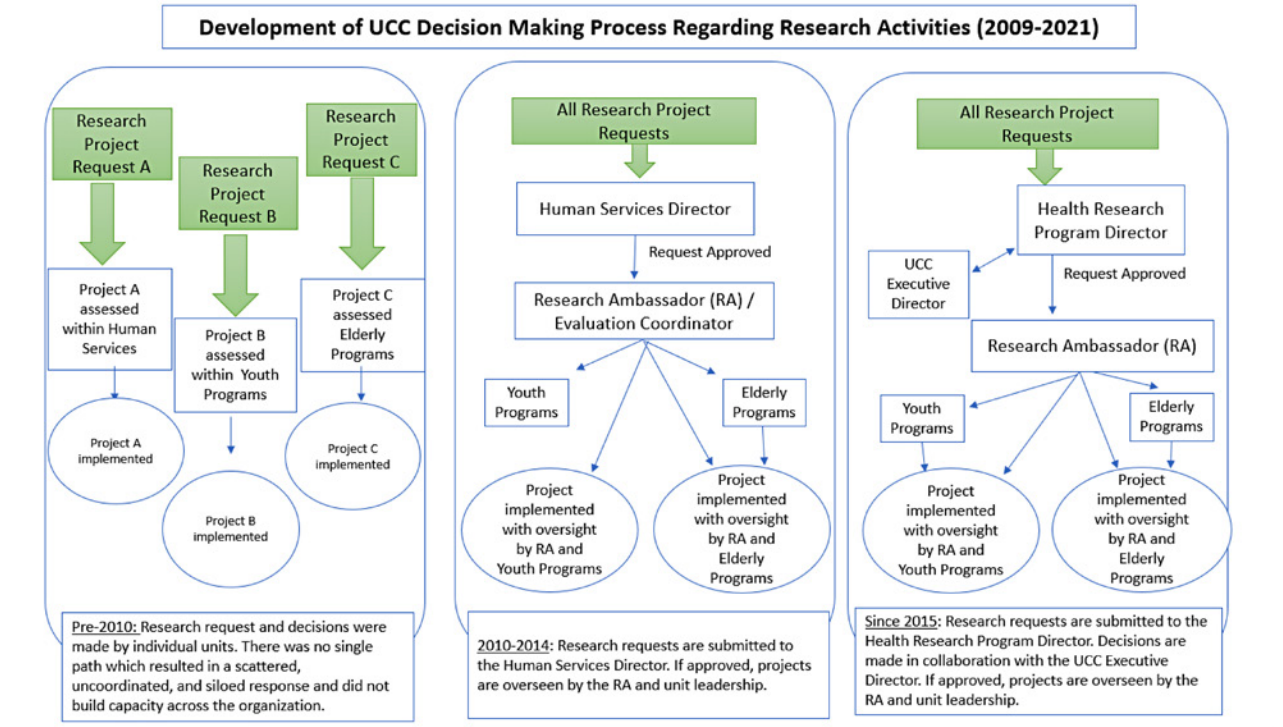
18. Santiago-Torres M, Cui Y, Adams AK, et al. Familial and individual predictors of obesity and insulin resistance in urban Hispanic children. Pediatr Obes. 2016;11(1):54–60.

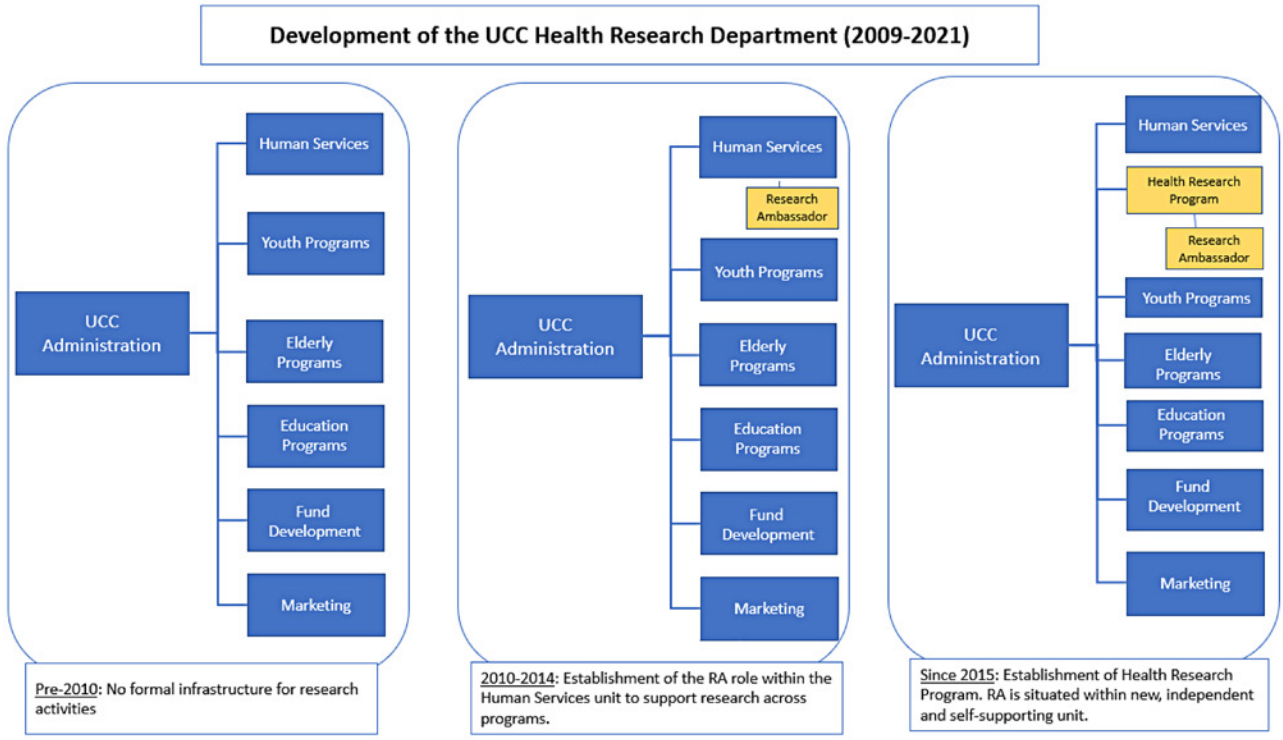
19. Jacquart SR, Schoeller DA, Adams AK, et al. A pilot study evaluating the feasibility of a summer gardening program to prevent summer weight gain in overweight adolescents. FASEB J. 2010;24(1 Suppl):741.7–741.7.

20. Carrel AL, Sledge JS, Ventura SJ, Eickhoff JC, Allen DB. GPS suggests low physical activity in urban Hispanic school children: A proof of concept study. Int J Pediatr Endocrinol. 2014;2014(1):25.

21. Kim JE, Medic V, Castro A, et al. Teleophthalmology in a community setting to improve eye health among Latinos: A paradigm shift. Invest Ophthalmol Vis Sci. 2016;57(12).

APPENDIX 1: UCC HEALTH RESEARCH PROGRAM INFRASTRUCTURE





APPENDIX 2: UCC FUNDING HISTORY