

Formative Research Team: Example Collaborations

I. Food Insecurity

Project Title: Impact of Home Delivered Produce on Food Security, Household Budget, and Diet in Families with Young Children: A Mixed Methods Pilot Study

The Formative Research Team partnered with principal investigator [Laura Plencner, MD](#), to understand the impact of a produce delivery program on the food security, budget, and diet in food insecure families.

This mixed methods pilot study engaged 51 families who were already enrolled in a home visiting program, with the formative research team leading the qualitative part of the study. In collaboration with Dr. Plencner, the team designed the interview guides, conducted the in-depth interviews with both English and Spanish speakers, analyzed data and wrote up the qualitative findings.

Related publications / presentations:

- Plencner LM, Ross JN, Hall M, Hurley EA, Raphael JL, De Miranda ED, Colvin JD. Piloting Home Produce Delivery to Improve Food Security, Budget, and Diet in Families with Children: A Mixed-Methods Study. *Academic Pediatrics*. 2024 Aug 2. [10.1016/j.acap.2024.07.017](https://doi.org/10.1016/j.acap.2024.07.017)

II. Genomics

Project Title: Ethical, Legal & Social Issues in Pediatric Genomics

FRT collaborates with [Courtney Berrios, MS](#) and colleagues in Children's Mercy's internationally renowned pediatric [Genomic Medicine Center](#) to find ways to put patients and families at the center of genomic medicine, and better understand the ethical, legal and social issues related to genomic and rare disease research.

Through multiple projects, we have partnered to explore issues with how genomic sequencing results are communicated to families, create a patient-and family-driven research agenda for research on rare conditions, and understand stakeholder perspectives on ethical issues related to the use of organoid models. FRT contributed to qualitative design, conduct and analysis of in-depth interviews, and training of parent partners in focus group moderation.

Related publications / presentations:

- Berrios C, Hurley EA, Willig L, Thiffault I, Saunders C, Pastinen T, Goggin K, Farrow E. Challenges in genetic testing: clinician variant interpretation processes and the impact on clinical care. *Genetics in Medicine*. 2021 Dec 1;23(12):2289-99. <https://doi.org/10.1038/s41436-021-01267-x>
- Berrios C, McBeth M, Bradley-Ewing A, Schuetz N, Campbell A, Talebizadeh Z, Garrett JR, Falicov T, Martinez F, Hurley EA. Developing a community-led rare disease ELSI research

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agenda. Orphanet Journal of Rare Diseases. 2024 Jan 22;19(1):23.

<https://doi.org/10.1186/s13023-023-02986-x>

III. Global Health

Project Title: Barriers and Facilitators to Long-Acting Reversible Contraception: Perspectives of Adolescents and Young Adults and Healthcare Providers in Rural Haiti.

The Formative Research Team collaborated with Dr. Abbey Masonbrink, to identify strategies to increase autonomy-supportive access to highly effective contraception and menstrual management among young people in Haiti.

Partnering with Dr. Masonbrink's research team and local communities in rural Haiti, the FRT designed the interview guides and surveys to identify menstrual management issues, as well as the facilitators and barriers to contraception use among rural adolescents and young adults in rural Haiti.

Related publications / presentations:

- Masonbrink AR, Hurley EA, Schuetz N, Rodean J, Rupe E, Lewis K, Boncoeur MD, Miller MK. Sexual behaviors, contraception use and barriers among adolescents and young adults in rural Haiti. BMC Women's Health. 2023 Mar 27;23(1):137. <https://doi.org/10.1186/s12905-023-02268-5>
- Wooten S, Hurley E, Schuetz N, Miller MK, Rodean J, Rupe E, Lewis K, Boncoeur MD, Masonbrink AR. Barriers to pregnancy prevention for adolescents in rural Haiti: perceptions of healthcare providers. BMC Women's Health. 2024 May 22;24(1):305. <https://doi.org/10.1186/s12905-024-03136-6>
- Rupe ER, Rodean J, Hurley EA, Miller MK, Boncoeur MD, Masonbrink AR. Menstrual health among adolescents and young adults in rural Haiti. Reproductive Health. 2022 Dec 20;19(1):227. <https://doi.org/10.1186/s12978-022-01533-4>

IV. Rural Adolescent Sexual Health

Project Title: Understanding the health needs of Latinx youth living in rural communities.

FRT partnered with [Dr. Romina Barral](#), to develop and test an intervention aimed at preventing unintended teen pregnancy (TP) among Latinx teens living in rural Kansas.

The Formative Research Team worked with Dr. Barral to design and translate interview materials into Spanish, conduct Spanish research sessions, and analyze collected data to meet the study's three aims: 1). Explore Parent/Caregiver and Adolescent Healthcare Providers knowledge on current teen pregnancy prevention resources and their perspective on what a teen pregnancy prevention program for Rural Latinx youth would look like; and 2). Facilitate co-development sessions with Rural Youth and

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their caregivers to modify the “*Cuidate*” curriculum to better fit rural youth needs; and 3). Pilot the redesigned curriculum among rural youth. This is an ongoing project.

V. Community Health Workers

Project Title: Connecting People to Care: Mapping the Community Health Workers (CHWs) Community Referral Process

The Formative Research Team partnered with principal investigator [Helena Laroche, MD](#), to examine the facilitators and barriers CHWs face in providing successful social service referrals to clients. The study aims to create a process model to guide effective referral systems.

This study engaged 20 Community Health Workers (CHWs) from two community-based organizations in Kansas and Missouri. The FRT led the qualitative arm of the mixed methods study in co-designing the interview guides, conducting the in-depth interviews and several member-checking sessions, and analyzing data leading to dissemination at several national and regional public health conferences including the American Public Health Association, the Society for Public Health Education and NACCHO360.

Related publications / presentations:

- Lartey, Lynette; Hurley, Emily A.; Chrans, Mariah; Ochoa, Kevin; and Laroche, Helena, “Mapping CHW Community Resource Referral Processes: A Qualitative Study.” (2024). *Research at Children's Mercy Month 2024*. 29.

https://scholarlyexchange.childrensmercy.org/research_month2024/29

VI. Healthy Lifestyle and Nutrition.

Project Title: From Assessing to Connecting: A Formative Research Study for Pediatric Patients with Physical Activity and Nutrition Needs

The Formative Research Team partnered with principal investigator [Robin Shook, PhD](#), with the Center for Healthy Lifestyles and Nutrition, to study and design an electronic health records-based referral system to connect pediatric patients to community-based nutrition and physical activity resources.

The FRT designed data collecting tools which included a survey, in depth interview guides, and focus group guides, and collected data from multiple stakeholders within the pediatric settings. Stakeholders included healthcare providers, hospital leadership, a bioinformatics team, parents who sought care for their children at a pediatric hospital, and representatives from community-based nutrition and physical activity organizations. Preliminary findings were presented at the American Public Health Association, and American College of Sports Medicine conferences, and a manuscript of findings is forthcoming.