PROJECT SUMMARY

PROJECT TITLE: Measuring and improving maternal and child health outcomes through tablet-based data collection and educational outreach among refugee women in Clarkston, Georgia.

RELEVANCE: Per the United Nations, a refugee is "someone who has been forced to flee his/her country because of persecution, war, or violence." At the end of 2015, there were more than 3,000,000 refugees in the United States, and Clarkston, just outside Atlanta, is one of nine major resettlement areas where more than 18,000 refugees live. In addition to language and cultural differences, refugees face tremendous challenges while traversing our healthcare system, particularly during pregnancy and childbirth. A Clarkston-based nonprofit, Friends of Refugees, addresses this issue through their project, "Embrace Birth." Embrace provides education and pregnancy/labor support to refugee women, and in that capacity, hears reports of local healthcare providers failing to explain or gain consent for invasive medical procedures due to cultural and language barriers. This raises questions about the actual and perceived quality of care and health outcomes for refugee women and children; but unfortunately, there is little data on refugee health in the U.S.

We therefore propose to implement a student research grant to partner with Embrace to launch the first population-based survey of refugee maternal and child health in Georgia. We propose digitizing the survey and administering it with Android tablets and ODK software to improve overall cost, data quality, and implementation. Measured variables will include delivery type, outcomes, medical interventions, quality of care, knowledge, attitudes, beliefs, barriers, and cost. We will then present the data to area healthcare providers to encourage discussion about improved cultural competency, while also using the data to refine, film, and digitize Embrace's educational curriculum for tablet devices.

Our long-term goal is not only to contribute to the improvement in accessibility, quality, utilization, and outcomes of birth care among refugees here in the Atlanta area, but also to develop scalable results, tools, and processes that can be disseminated and used in other refugee communities throughout the United States. We have intentionally chosen tablet-based administration use free, open-source software for both survey implementation and subsequent educational provision to facilitate replicability at scale.

PROJECT SITE: This project will be implemented among refugee women of reproductive age who have had a birth in the metro Atlanta area in the two years preceding the survey. Approximately 300 surveys will be conducted with intentional sampling of all major ethnicities and nationalities in the area.

KEY PERSONNEL: Students on our team include:

- Principle Investigator: Jacqueline Cutts, Accelerated Bachelor of Science in Nursing program, Emory University Nell Hodgson Woodruff School of Nursing. Jacqueline holds an MPH in Global Health with a Certificate in Maternal and Child Health from Emory, and a BA in Political Science from Vassar College. Jacqueline's background is in global maternal and child health, having founded a lead a maternal health focused nonprofit in

Uganda, called Safe Mothers, Safe Babies, for the past eight years. In this capacity, Jacqueline has gained extensive experience developing and implementing population-based research projects to measure health outcomes and utilize the data for evidence-based interventions. Jacqueline started working with Embrace at the beginning of this year, helping to teach childbirth education classes, provide labor support directly to refugee women, and develop this research project. Email: jcutts@emory.edu.

- Co-Investigator: Melissa Garner, Accelerated Bachelor of Science in Nursing program, Emory University Nell Hodgson Woodruff School of Nursing. Past degrees: BA in Anthropology. Melissa's background is in healthcare as a rehab tech and as a health advocate, with special interest in increasing knowledge and practice of good breastfeeding skills among vulnerable, low-income women. Melissa has a special affinity for birth-related issues given her own two births, and has volunteered for Embrace off and on for the past three years. Email: mgarne@emory.edu.
- Co-Investigator: Rebecca Hutchins, Master of Business Administration program, Georgia Tech Scheller College of Business. Past degrees: MS in Forensic Science, BS in Microbiology. In addition to pursuing her business education, Rebecca currently work as a medical scientist consultant on public health research projects, among them the development of an Infectious Disease Outbreak data management solution and a multi-agency collaboration to enhance pathogen discovery through next generation sequencing and bioinformatics. Now as a business student, Rebecca's interests center on the sustainability and cost-related aspects of public health interventions and issues. Email: rhutchins8@gatech.edu.
- Co-Investigator: Tyler Fuller, Master of Divinity/Master of Public Health joint degree program, Emory University Candler School of Theology and Rollins School of Public Health. Past degrees: BA in Biology and Religion. Tyler is a returned Peace Corps volunteer whose experience and interests lie in the intersection of maternal, child, and reproductive health with health beliefs based on religion, culture, and education. Email: tyler.john.fuller@emory.edu.
- Co-Investigator: Richard Cutts, Medical Doctor program (4th year), Emory University School of Medicine. Past degrees: BS in Exercise Science. Richard is a fourth-year medical student seeking to go into general surgery. He has spent the past six years working in Uganda on global health issues in partnership with his wife, Jacquie, the study's PI. His interests include the quality of care provided from physicians and its impact on long-term healthcare behavior, particularly in a global population context. Email: richard.paul.cutts@emory.edu.
- Co-Investigator: Dr. Pierre Kwizera, Master of Public Health program, Emory University Rollins School of Public Health. Past Degrees: MBChB (Medical Doctor). Dr. Kwizera is a native of Burundi pursuing a Master of Public Health degree through Emory's Humphrey Fellows Program. Dr. Kwizera's work experience is extensive, having worked with the Burundi Ministry of Health to implement an innovative health financing approach called Performance-Based Financing, and having worked throughout East Africa on clinical capacities and health research in maternity, sexual and reproductive health, and HIV. He speaks French, Kirundi, and Kinyarwanda, and has a unique understanding of several of the East African cultures, languages, and healthcare systems from which refugees in the Atlanta area come.

FACULTY ADVISER: Our team will be mentored by Dr. John Cranmer, an Assistant Professor in the Emory Nursing School and the Specialty Track Coordinator for the Population Health track of the Doctorate of Nursing Practice Program. With extensive experience on interdisciplinary and translational maternal and child health research both in the U.S. and abroad in Kenya, Ethiopia and India, Dr. Cranmer will offer invaluable guidance in the development of the project and translating the results of the research into tangible evidence-based interventions. Dr. Cranmer can be reached by email at: john.cranmer@emory.edu.

OTHER KEY CONTRIBUTORS: Our team will work extensively with the team members of the Embrace Birth project. These include:

- Jenny Cochran, Director: Jenny Cochran is the Director of Embrace and responsible for shaping and implementing Embrace Birth programs. Her background is in childbirth education and labor support as a doula.
- Heidi Miller, Community Liaison: Heidi Miller is the Community Liaison for Embrace, focused on working directly with refugee women and their families. Her background is in social work and labor support as a doula.
- Merry Seing Pai, Chin Community Ambassador: Merry is a Burmese refugee who went through the Embrace program when pregnant with her second child. Merry is Embrace's Ambassador to Chin refugees (from Burma), providing translation services and assisting with outreach to the Chin community.
- Pet Pet, Karen Community Ambassador: Pet Pet is a Burmese refugee who went through the Embrace program when she was pregnant with her first baby. She is Embrace's Ambassador to Karen refugees (also from Burma), working as a Karen translator during classes and assisting with outreach to the Karen community.
- Tarumbeta Obed (Obed), African Community Ambassador: Obed is a Congolese refugee who connected with Embrace while his wife was pregnant with her seventh baby. Obed has fluency in seven languages and a background as an HIV counselor. He not only provides translation services in multiple languages, but also assists women to their doctor's appointments, helps them fill out medical paperwork, and acts as a connection to other community resources.
- Muzhda, Afghani Community Ambassador: Muzhda is an Afghani refugee who went through the Embrace program while pregnant with her first child. She is Embrace's Ambassador to Afghani refugees, providing translation services and assisting with outreach to the Afghani community.

HUMAN EMBRYONIC STEM CELLS: Not applicable.

Project Narrative

1. Study Aims and Objectives:

Study Aim:
To assess the health experiences and outcomes of maternal and child health services among refugee women living in Clarkston, Georgia; compare results of Embrace clients with non-embrace Clients; and develop/refine evidence-based interventions to better address refugee birth education and provider knowledge/behavior based on the results of the assessment.

Specific Objectives:

1. Evaluate prevalence of the population prevalence of indicators related to maternal and child health in Clarkston, Georgia:
    - Prenatal care attendance
    - Perceived quality of prenatal care
    - Medical interventions during pregnancy and birth
    - Intrapartum complications
    - Delivery type and outcome
    - Perceived quality of delivery care
    - Breastfeeding initiation at birth, exclusivity, and age of cessation
    - Utilization and timing of postnatal care for both mother
    - Perceived quality of postnatal care
    - Knowledge of pregnancy, birth, breastfeeding, and postpartum care facts
    - Attitudes of and beliefs about birth, medical interventions, breastfeeding, and the U.S. healthcare system
    - Barriers to accessing medical care during pregnancy, birth, and the postpartum period
    - Costs incurred to access care during most recent pregnancy
2. Present results to local obstetric providers to begin respectful discussion about refugee experiences of maternal and child health services and its relationship to long-term outcomes and care-seeking behaviors.
3. Refine existing educational curriculum and adapt to illiterate or ESL populations through revision of curriculum, digitization of instruction into video, and placing it on a tablet and website for greater accessibility to evidence-based education.
4. Compare results of Embrace clients with non-Embrace clients to assess current strengths and opportunities among partner organization's projects.

2. Design

A. Study Design

This study is a cross-sectional case-control study with subsequent tailoring and development of interventions based on study results.

Activities and Timeline
The project consists of five phases:

1. Pre-Survey Phase: Stage characterized through interdisciplinary refining of survey materials through student partnerships, professor mentorship, and review with partner organization; translation of the survey into major languages spoken by refugees in Clarkston; digitization of the survey; setup of online server for survey storage; purchase of tablets; loading of surveys on the tablets; testing the survey to identify/fix errors; and development of enumerator training program.
2. Survey Implementation Phase: Stage characterized by training of enumerators and physical implementation of the survey.
3. Data Analysis and Intervention Development Phase: Data will be analyzed and used to assess the Study Aim and Objectives described in Section 1. Results will then be used by the interdisciplinary team to plan for the educational refinement and provider presentation of data, described further in the "Intervention Phase."
4. Intervention Phase: Data will be used in three primary ways:
    a. Refining Embrace educational curriculum: Study team will work with Embrace to refine their educational curriculum, teach the Embrace translators (who will double as our enumerators) to teach the curriculum themselves in their major languages of fluency, video record the instruction, digitize it, and disseminate it both through tablet-based programs that volunteers can utilize during in-home visits and also through a multilingual website for refugees to access either at home, on their phones, or at the Friends of Refugees computer/Internet café.
    b. Discussion with local obstetric providers: Study team will prepare a series of data presentations to spark discussions with local obstetric providers. We have already identified a local obstetrician who we believe could be an impetus for facilitating these meetings and stimulating provider behavior change. Although some refugees have had challenges with this obstetrician, our interactions with her indicate that she cares deeply about the refugee population but perhaps lacks some of the knowledge of how to provide culturally humble care. We feel that if we engage her on our team from the beginning of survey development, that she will then be better prepared to help organize meetings for data presentation and discussion with her fellow obstetric providers.
    c. Dissemination of results: Study team will present results through publication and conferences, and will also disseminate the tools (surveys, videos, curriculum) developed during the project. Our goal is to encourage measurement activities and the development of truly evidence-based interventions among refugee organizations and populations in other cities throughout the U.S.
5. Ongoing Monitoring and Evaluation: We will monitor our progress throughout intervention implementation and hope to evaluate our interventions through a repeat population-based survey with added qualitative interviews two years later.

B. Sample, Risks, and Benefits to Participants

Population:

Survey respondents will be refugee women of reproductive age (18 – 49) residing in Clarkston, GA who have had a birth in the two years prior to the study. Educational program beneficiaries will include pregnant refugee women in the same region who are clients of our partner, the

Embrace Birth Project. Provider discussions will be held with local OB/GYNs and midwives who provide birth services to refugee populations in Dekalb County, Georgia.

Inclusion/Exclusion Criteria:
Survey respondents will be refugee women of reproductive age (18 – 49) who had a birth in the two years prior to the study and live in Clarkston. No additional exclusion criteria.

Risks and Risk Mitigation for Participants and Vulnerable Populations:
The survey will only be administered to women who have had a baby in two years preceding the survey, but could include pregnancy women if they had a pregnancy previously but are pregnant again. The administration of the survey poses no more than minimal risk to any participant, including pregnant participants. Risks are limited to discomfort talking about reproductive health topics and potential for loss of confidentiality if the data was stolen.

To mitigate these risks, care has been used to only ask questions of direct consequence to the study, and to avoid topics that would be unnecessarily uncomfortable and pose extra risk to the participants (such as HIV and domestic violence). Care has also been taken to protect respondent privacy and confidentiality through the use of password-protected tablets, an online secure server that is password protected for data storage, and the numeric coding of patient identifying information in the survey such as locations. Finally, the enumerators will have at least one team member acting as a field supervisor during data collection. This individual will monitor each of the enumerators to ensure compliance with informed and non-coercive consent and interview processes. Training will be ongoing based on an iterative management process.

Benefits to Participants
Some of the participants already benefit from Friends of Refugee/Embrace Birth programs. But the results will hopefully result in an improvement and expansion of Embrace services, improved willingness of healthcare providers to provide culturally sensitive care, and better evidence-based interventions to benefit refugee health and rights among the refugee community on the whole.

C. Setting

Location:
Data will be collected through face-to-face interviews in which surveys will be conducted in private locations, in or near the respondent's homes to help ensure confidentiality.

D. Recruitment

Recruitment Site and Procedures:
The study will utilize a two-stage cluster design using probability proportionate to population size sampling methods. We will obtain population distribution information and divide Clarkston into small clusters, then conduct a systematic random sampling to select required clusters.

Survey implementation will begin at a location randomly selected within a cluster. We will intentionally put enumerators within clusters known to have a large majority of people who speak a language in which the enumerator is fluent. If an enumerator identifies a household in

which there is a language barrier, the enumerator will contact the enumerator on the team who can speak the respondent's language and will seek to set up an appointment for the appropriate enumerator to conduct the interview. Once the appropriate enumerator is with a respondent who speaks his/her language, the enumerator will identify an eligible woman of reproductive age, invite them to participate in the survey using a standardized script that ensures complete voluntary participation, and obtain informed consent prior to beginning the survey.

Recruitment Methods:
Trained enumerators will approach sampled houses and ask to speak with the woman of that household. The enumerator will explain the purpose of the study, what answering survey questions will include, and all aspects of informed consent. A pre-written script located at the beginning of each survey will aid this process. The enumerator will then ask eligibility questions. If a respondent meets eligibility criteria, the enumerator will ask the respondent whether she has any questions, answer any questions, and ask if she is willing to participate in the interview. Only women from sampled houses who meet eligibility criteria and are willing to participate in the study following informed consent will be recruited to complete a survey.

Monitoring Equity in Recruitment:
Probability proportionate to population size cluster-based sampling and starting in a random spot in selected clusters will ensure that all eligible individuals have an equal chance of being selected for participation. This will help safeguard the representativeness of the sample. Due to the potential for clusters of similar nationalities to live together, care will be taken to monitor the ethnic/national makeup of survey respondents as surveys are completed and comparing them to demographic data of the overall ethnic/nationality makeup of Clarkston with the intent to revise survey sampling methods if they end up unintentionally skewing survey results.

E. Measures

Topic Areas:
Modules that will be included in the baseline survey include:

- Demographics: Respondent age, country of origin, languages, marital status, educational attainment, household size, financial capacity, and household asset ownership.
- Pregnancy History: Number of lifetime pregnancies and births.
- Detailed Pregnancy History of Most Recent Birth: Progression, experience, and perception of prenatal, intrapartum, and immediate post-partum care; assessment of interventions; outcomes; and access to and utilization of prenatal health education.
- Newborn Care: Newborn care at birth and breastfeeding initiation and continuation.
- Knowledge, Attitudes, and Practices about Pregnancy and Childbirth: Respondent's knowledge, attitudes, and practices regarding pregnancy, birth, and early infant care.
- Friends of Refugees/Embrace Services: Exposure to and perception of Friends of Refugees programs, with a focus on Embrace services.

F. Data Analysis:

Rationale for Sample Size:

We aim to collect information regarding knowledge, attitudes, and practices that are related to mortality, morbidity, health outcomes, and more directly related to our partner organization itself, as detailed in a prior section. We will try to assess mortality, but realize that mortality requires such a large sample size that our ability to collect that data might be limited.

Given that many of these topics have not been studied in this population at all, and thus have not been reported for us to make precise point estimates, we hope to obtain a minimum of 300 completed surveys which we anticipate will get us the largest sample size possible with consideration to the budget allocation.

Data Management and Statistical Analysis:
Data entry will consist of uploading the surveys on each tablet to a secure online depository every night following fieldwork. Data will be checked for accuracy every day and corrected with enumerators if required. However, electronic data collection should reduce data cleaning requirements. All tablets, computers, external hard drives, and the online data depository will be password-protected. Only investigators will have passwords to computers, external hard drives, and the online data depository. Enumerators will have the password to their individual tablet only, which will be linked to a user account with limited capabilities that does NOT permit manipulation or access of aggregate data.

Data will be imported into STATA 13.1 to be cleaned and analyzed following data collection. The team will use a variety of statistical methods to analyze data as appropriate. Likely methods will include Pearson chi square tests, t-tests, and/or multivariate methods (logistics and/or linear regressions based on type of outcome). The team will analyze each indicator on its own and across demographic factors (education level, marital status, parity, age group, and others). Baseline analysis will explore each indicator and test for associations, and will compare Embrace clients vs. non-Embrace clients.

G. Enumerator Training

We plan to train 3 – 5 enumerators depending on how many languages each enumerator speaks. Training will consist of 5 days of classroom training, 1-2 days of field testing the instrument in a non-selected cluster, and continual refresher training as necessary. Topics covered in classroom training will include an overview of maternal and child health topics, introduction to the survey, a detailed discussion of the survey components, instructions on conducting the survey, and problem mitigation procedures/strategies.

3. Confidentiality and Informed Consent

Surveys will be administered in private, most likely inside the respondent's home or immediately outside but away from other household members, neighbors, or other individuals. Verbal consent will be obtained privately in the respondent's home at the time of interview by trained enumerators using a script provided before beginning of each survey; we will conduct a verbal consent due to low literacy rates. Surveys will be conducted on tablets that are password protected, and will be uploaded to a password-protected computer and password-protected online database every night (then deleted from the tablets). Only study staff will have passwords.