Exploring the Role of Community Health Workers in Improving Uptake of Family Health History Assessment among Patients and Providers

1. BACKGROUND AND CONTEXT. Community health workers (CHWs) have been successful in engaging with underserved populations to improve access to services and promote health. As trusted members of their communities, CHWs have been shown to be effective, in part, because of their cultural competency and ability to capitalize on existing community networks [1, 2]. Indeed, health promotion and communication efforts are often better-received when delivered by CHWs than other sources [3]. Further, CHWs have been successful in disseminating a wide array of public health interventions, including the prevention, treatment, and management of chronic diseases [1, 4-6]. CHWs are also well-recognized for their ability to be a bridge between patients and healthcare systems, supporting bi-directional discussions that take into account individual’s understanding of their health [7].

Despite this large and consistent evidence-base supporting the value of CHWs for health promotion, it is somewhat surprising that there has been limited effort to involve CHWs in the dissemination of evidence-based genomic recommendations related to common health conditions. For example, efforts such as the Surgeon General’s Family Health History (FHH) initiative and the Evaluation of Genomic Applications in Practice and Prevention’s (EGAPP) recommended population screening for inherited cancers and heart disease will rely on broad-based dissemination efforts that up until now have largely not included CHWs [8, 9]. FHH can draw attention to concerns commonly associated with genetic risk, including history of multiple affected family members and early onset of disease; the FHH can also be used to identify environmental (social, physical, cultural) factors that influence an individual’s health [10]. Similarly, population screening to identify high-risk families and encourage preventive actions could be accelerated by engagement of CHWs who have high credibility in communities that have been skeptical of genomics [11-16]. Moreover, CHWs’ longstanding role in supporting general health promotion for common chronic diseases has yet to be explored with respect to use and effectiveness of FHH based risk assessments. Given the increasing ubiquity of genomic information in the public sector (e.g., 23&Me) and occurrence of high profile celebrities with inherited cancers, it is likely that community members may be initiating discussions about genomics and FHH with CHWs [17-20]. However, to date the extent of these conversations is largely unknown.

Knowledge of FHH information is a precursor for identifying individuals for these tailored, risk-stratified efforts to prevent complex chronic diseases and interpretation of genetic information [13, 21, 22]. While individuals recognize the importance of FHH in their own health, this belief has not translated into widespread adoption of FHH collection tools and gathering of relevant information among individuals [23, 24]. In fact, individuals report poor understanding of FHH information and limited knowledge about FHH collection [25]. Knowledge about genomics and FHH is lower among minorities (who may already be at increased risk for heritable diseases) and those with limited literacy, which impacts the likelihood of communicating FHH information with physicians [26].

Relatedly, although collecting basic FHH is a cornerstone of medical practice, evidence suggests that FHH information is under collected and underutilized in clinical practice. While patients are interested in sharing information with physicians about their health history, this information is often not elicited from patients and the information collected is frequently not comprehensive enough to develop tailored disease prevention and personalized recommendations [27-32]. Often this information is one-directional and only discussed at new patient visits, not future visits [33]. Indeed, FHH is a living document and requires continuous updates and ongoing conversations. The lack of collection may be influenced by limited time, poor genomic literacy among providers, and competing demands with physicians [34-36].

The CHW workforce is optimally positioned to support broad-based dissemination of genomic advancements. CHWs have skills and experience in engaging individuals, families, and providers in conversations about health that could logically include FHH. Further, because of their ongoing, close relationships with community members, CHWs may already be engaged in conversations related to genomics and FHH. However, there is a dearth of information about whether and to what extent CHWs are already communicating about FHH and genomics more broadly. The Diffusion of Innovations (DOI) and Consolidated Framework for Implementation Research (CFIR) can be applied to consider potential opportunities and challenges for engaging CHWs in dissemination of genomic information. These theories provide frameworks for assessing the likelihood that, and pace at which, novel ideas are adopted and include consideration of barriers and facilitators to uptake. Together these frameworks suggest that some CHWs are likely to be receptive earlier to integrating genomics into their health promotion activities than others, and that some contexts are likely to be more elucidative of these discussions than others. Using theoretically-driven aims guided by the DOI and CFIR, this pilot study will be
among the first to explore the current state of CHWs’ work in genomics and FHH and perceived opportunities for capacity building among the workforce.

2. GOALS AND SPECIFIC AIMS. We seek to explore opportunities to extend CHW roles in gathering and sharing FHH information. In this pilot study we propose to conduct semi-structured interviews with CHWs to gain their opinions and experiences about their potential role in disseminating evidence-based FHH assessment and screening for inherited diseases. Drawing from the DOI and CFIR to inform opportunities for capacity building [37], we will engage CHWs at Morehouse School of Medicine (MSM) to examine specific beliefs about FHH, current work with patients around this issue, and opportunities for future use of FHH. Specifically, we aim to:

Aim 1. Examine CHW’s current engagement in FHH collection, beliefs about the importance of FHH collection, and self-efficacy about FHH and contexts in which these discussions are occurring. We will conduct semi-structured qualitative interviews with CHWs recruited from MSM’s CHW training program (past and present trainees) to examine their perceived value of collecting FHH and alignment of FHH collection to their current work. During the interviews, we will explore the existing ways and contexts in which CHWs are (or are not) engaged in FHH collection and related risk screening through informal and formal conversations with clients and providers.

Aim 2. Assess knowledge, training needs, and future opportunities to incorporate FHH into CHW roles by assessing the utility of FHH tools. We will assess CHW’s perceived training and anticipated support needed to incorporate FHH collection into their current role. In addition, we will gather CHW’s perspectives about the quality of two existing FHH tools to help identify opportunities for CHWs to use these tools in their practice.

3. APPROACH. Below we describe our team, the study design, and the methods mapped onto each Aim.

Project Leadership. Our research team is comprised of professionals in public health, medicine, health communication, and biological sciences. Caitlin G. Allen, MPH (PI) is a doctoral student in the Dept. of Behavioral Sciences and Health Education in Emory’s Rollins School of Public Health. Her research focuses on genomic health literacy and ways to enhance the uptake of genomic applications, including FHH among minority populations by engaging non-traditional workforces such as CHWs [38]. Her relevant methodological experience includes quantitative and qualitative data collection and analysis, with a special focus on engaging CHWs in qualitative research efforts [39-41]. She is particularly well versed in studying CHW workforce development and has been deeply engaged in local, state, and national efforts to enhance CHW training [42-44]. She will oversee all aspects of the study including the interview guide development, conduct of interviews, and qualitative data analysis.

Brittaney J. Bethea, MPH (co-I) is a second year doctoral student in the Dept. of Communication at Georgia State University and Director of Marketing and Communications (Research Enterprise) at MSM. Her research focuses on the interplay between mass media use and interpersonal communication and the effects on health attitudes, beliefs, and behaviors. Her relevant methodological experience includes focus group and in-depth interview facilitation and analysis. She will conduct interviews and lead the development of the codebook and qualitative analysis process. Ms. Bethea is a Certified Communicator in Public Health with communications research and evaluation skills relevant to determining whether data can help meet the public health communication needs of intended audiences and applying research-based findings to public health communication practice.

Lawrence P. McKinney, BS (co-I) is a master’s student at MSM’s Master of Public Health Program. His relevant methodological experience includes quantitative and qualitative data collection and analysis, with a special focus on cancer health disparities and public health genomics research. In his current role as a Graduate Research Assistant, he is involved in studying how tailored health information technology tools such as iPad, can be used in combination with patient navigators to educate and provide guidance to patients during their initial stages of survivorship, contributing to improved quality of life of prostate cancer survivors. He will assist in developing the CHW guide, scheduling CHW interviews, conducting interviews and qualitative data analysis. All students will work together to develop abstracts and manuscripts for dissemination.

Cam Escoffery, PhD, MPH (mentor) is an Associate Professor in the Dept. of Behavioral Sciences and Health Education in Emory’s Rollins School of Public Health. Her expertise includes dissemination and implementation research in chronic disease prevention among racial-ethnic minority groups [45-47]. Colleen McBride, PhD (mentor) is the Grace Crum Rollins Chair and Professor in the Dept. of Behavioral Sciences and Health Education. Dr. McBride is an international leader with two decades of research and publications related to intervention trials that evaluate genetic risk communication approaches in a variety of settings [48-51]. Together, Drs. Escoffery and McBride will oversee all aspects of the proposed study. The team will work closely in partnership with MSM’s Prevention Research Center and CHW training program. Collaborators at MSM include Tabia Akintobi, PhD, MPH (site partner), who is an Associate Professor, Associate Dean, and Prevention Research Center Director at MSM’s
Dept. of Community Health and Preventive Medicine. Dr. Akintobi leads and evaluates federally funded community-engaged research capitalizing on the leadership and skills of CHWs. Gail McCray, MA (site partner), is an instructor and CHW Program Director at MSM’s Dept. of Community Health and Preventive Medicine.

**Preliminary Work.** Our team has conducted preliminary work in the area of FHH, genomics, CHWs, and related fields. In addition to the previously cited studies about CHWs and genomics, Caitlin G. Allen has led a systematic review of FHH tools focusing on tools that have been used in community and clinical settings. These results are not currently published but guided selection of the tools that will be tested in Aim 2 of the study. In addition, she has completed secondary data analysis alongside Drs. McBride and Escoffery to identify multilevel influences of individuals’ perceived importance of FHH to their health. Findings from this work are specific to patients who CHWs may work with and have helped to hone the key set of characteristics that make FHH collection more or less likely among individuals. Brittaney J. Bethea collaborated with a workgroup at the CDC to develop a community-clinical linkages guide that highlights key strategies and case examples for the implementation of community-clinical linkages often leveraging the role of CHWs [52]. Lawrence P. McKinney’s thesis work involves research on how genetic causal beliefs differ across racial and ethnic groups with respect to testing for cancer risk. The results of this research are not currently published but have informed the interview guide that will be used. Mr. McKinney also has years of experience in recruiting and educating patients on the risk and benefits of donating tissue samples for research and biobanking purposes. Collectively, the proposed methods and study are built on prior research and experiences of the team of students.

**Aim 1.** Examine CHW’s current engagement in FHH collection, beliefs about the importance of FHH collection, and self-efficacy about FHH and contexts in which these discussions are occurring.

**Design.** We will conduct qualitative interviews with up to 30 CHWs to examine their perceived value of collecting FHH and alignment of FHH collection to their current work. During the interviews, we will explore the existing ways CHWs are (or are not) engaged in FHH collection through their conversations with clients and providers.

**Procedures and Participant Selection.** We will conduct semi-structured interviews with up to 30 CHWs who have been part of the MSM CHW training program. We will recruit participants from existing, past, and present training cohorts (recruitment facilitated by Gail McCray and Dr. Tabia Akintobi, see letters of support). We will purposively select interviewees to gather a diverse range of experiences (e.g., gender, years practicing as CHW). Selected participants will be contacted via phone and scheduled to conduct an in-person interview. Researchers will introduce the interview process, purpose, and incentive to participate ($50 gift card per participant). We will attempt to reach each participant no more than three times over a two-month period in order to establish our interview sample.

**Semi-Structured Interviews.** Student investigators will schedule participants for the semi-structured interview at a time convenient to the participants. Participants will be sent email reminders/phone call the day before and the day of the interview. Each semi-structured interview will be conducted in person, roughly 75 minutes long, audio-taped, and guided by standard principles of qualitative methods. One of the three students from the research team will conduct the interview. All three students have qualitative interviewing experience. Our mentors, Drs. Escoffery and McBride also have extensive experiences in conducting interviews and will oversee the entire interview process.

**Measures.** An investigator-designed interview guide will be used to collect data. The interview guide will address the aims of the project and are guided by the constructs from the DOI and CFIR (see Table 1).
Data Analysis. All interviews will be digitally recorded and transcribed by a professional transcription service (Matchless Transcription, see additional materials). Qualitative data will be analyzed using standard principles of qualitative methods in MaxQDA, a qualitative data analysis tool. The highest level of validity and reliability will be obtained throughout the qualitative analysis process. Three coders (students on the team) will independently review transcripts, generate preliminary codes, and meet to refine the primary and secondary code definitions in a structured codebook. Then coders will independently code transcripts, applying the agreed upon codes. Independently coded transcripts will be compared for discrepancies and consensus reached. Transcripts will be re-coded using the final consensus outlines. Matrices of key codes and constructs and salient themes will be presented.

Aim 2. Assess knowledge, training needs, and future opportunities to incorporate FHH into CHW roles by assessing the utility of FHH tools.

Design. To address Aim 2, at the end of each interview we will provide CHWs with a FHH tool and discuss the relevance and utility of the tool to their work. In addition, we will gather CHW’s perspectives about the quality of the FHH tools to help identify future opportunities for CHWs to use these tools in their practice.

Procedures and Participant Selection. Questions related to knowledge and perceived training needs will be included in the interview. The analysis of specific tool features will also be completed as part of the previously described interview process.

Data Collection. Knowledge and training needs questions will be assessed as part of the qualitative interview data collection process. Information about the participant’s perceptions of the specific tool will be gathered during the interview. The interviewer will share a specific FHH tool (Surgeon General or Family Healthware) and ask questions about the tool (see additional materials). Responses will be recorded and transcribed. Half of the participants will be randomly assigned to assess each tool [53, 54].

Measures.

- Knowledge, Resources, and Training Needs. Through qualitative interviews, we will seek to identify perceived training and support needed to incorporate FHH into current practice (see Table 2).

- FHH Tool Quality Measurement. Half of interviewees will assess the Surgeon General’s FHH tool and half will assess Family Healthware. We will use previous surveys [7] to develop our assessment questions along with constructs from the DOI [25, 55, 56], which helps predict the likelihood of adopting a new innovation (see Table 3).

Data Analysis. All questions related to Aim 2, including the FHH tool quality measurement will be transcribed as part of the interview and coded as described previously. These data will help shape our understanding of next steps for engaging CHWs and practical ways FHH tools could be adapted for use by CHWs.

Timeline. Prior to beginning this study we will receive IRB approval from participating institutions. During the first two months of this project, we will finalize the draft interview guide and we will identify and recruit interview participants. In the following five months we will conduct up to 30 interviews with CHWs. In the final five months, we will transcribe interviews, complete interview data analysis, and write manuscripts.

4. ANTICIPATED RESULTS. We anticipate developing two manuscripts from the results of the proposed study. The first manuscript will focus on the findings from the qualitative interviews, specifically about CHW beliefs, self-efficacy, and current engagement in FHH. The second manuscript will focus on workforce capacity building and future opportunities to incorporate FHH into CHW roles and training. This manuscript will describe training needs and preferences for evidence-based FHH collection tools (comparing Surgeon General and Family Healthware). We also will submit abstracts to relevant state and national conferences, including the Georgia Public Health Association and American Public Health Association conferences being held in 2019.
The results from this study will also be applied to enhance the CHW training program at MSM. Specifically, we will identify whether CHWs are already engaging in collecting FHH information, the level at which they are engaging, and how these efforts could be reinforced to ensure accuracy and optimize health promotion efforts. If CHW engagement in FHH collection is considered feasible, then the next step would be to explore incorporating training about FHH into CHW curriculum and to pilot test CHWs using FHH tools with clients in primary care settings at MSM. This may include further evaluation of the completion of FHH information and use of FHH among providers.

Specifically, we will work with state-level partners to develop an infographic to post at clinics to help disseminate results into communities. Further, results will provide insight into ideal ways to engage CHWs in this role in the healthcare setting. This may include the use of a FHH collection tool or other strategies identified throughout the research process. CHWs working in this way would positively impact healthcare delivery by shifting the burden of FHH collection outside of the clinical setting, increasing the likelihood of accurate, robust information that would lead to stronger risk assessment.

The results from this proposed research are particularly timely as Georgia begins to consider CHW certification. The Department of Public Health is undergoing a review of CHW curriculum throughout the state (Caitlin G. Allen is engaged in this work). If this role is deemed feasible and useful for CHWs to engage in, there may be an opportunity to include FHH in core curriculum at the state-level or to develop additional modules that could complement core curriculum at the state-level. Indeed, if these findings are incorporated at the state-level, the results could help shape the future practice of CHWs in primary care settings across Georgia.

5. PROJECT SIGNIFICANCE. This pilot is among the first studies to explore the current state of CHWs’ work in genomics and FHH. There is emerging consensus that FHH is a key element of health records and is a valuable tool in clinical and public health settings [13]. From a healthcare improvement perspective, our ultimate goal is to improve FHH collection in order to provide personalized approaches to healthcare and prevention among individuals at higher risk for common and rare diseases. By identifying CHW roles in FHH collection, we will be better equipped to infuse training about FHH into existing CHW curriculum and further CHW understanding of the importance of FHH through additional training modules.

This project can positively impact healthcare delivery by allowing for improved collection of FHH and conversations between patients and providers. Improved collection of FHH may lead to improved screening, especially among high risk groups, which would help address healthcare costs by improving early detection, initiating personal healthcare plans, and developing tailored prevention efforts [57]. Knowing FHH can help improve personalized prevention approaches but requires patients to know the correct information, providers to collect FHH information, and make recommendations based on these findings [22].

Aside from improving healthcare delivery, long-term this project can serve to strengthen knowledge and awareness of FHH among clients seen by CHWs who may be at an increased risk for disease. Greater knowledge about FHH among the general population, particularly populations at a greater risk for common and rare diseases, will assist in the incorporation of precision medicine and public health genomic tools into clinical and public health settings in the years to come [58]. The collection of FHH information also serves to start a conversation. This conversation may help to empower individuals, which can have a positive impact on creating productive interactions with healthcare providers to take a proactive approach to family and personal health.

The proposed study serves as critical formative research in developing strategies to engage CHWs in the collection of important FHH information. The results of this study will inform future research that will benefit local and state CHW training, including opportunities to incorporate FHH into CHW roles. Finally, results from this study can help inform a larger research agenda that will assess systems issues for including FHH collection, engaging patients to understand how and why they are collecting FHH, and employing FHH information in medical shared decision-making.

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<th>Construct and Definition</th>
<th>Questions</th>
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<td>Relative Advantage: Perceptions of the advantage of the intervention versus an alternative solution (CFIR).</td>
<td>1. [If currently using another FHH tool] Do you see this tool as being an improvement over the current way you collect FHH? Why or why not? 2. [If NOT currently using FHH tool] How might using this tool help in your conversations with clients about their health?</td>
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<td>Compatibility: The degree to which there is a fit between intervention and needs or value system (CFIR).</td>
<td>3. Do you see this tool as being compatible with how you currently engage with clients? 4. Could you see yourself using this tool? Why or why not? 5. Do you think the tool would be most useful on paper or in electronic format? 6. Is use of this tool compatible with other education and assessment that you do with your clients?</td>
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<td>Complexity: The level of difficulty that the potential adopter encounters with the innovation; perceived difficulty of implementation (CFIR).</td>
<td>7. How difficult do you think it would be for you to use this tool with a client? 8. How would you rate your current client’s ability to complete FHH? 9. How easy would it be to talk about FHH with your clients and ask them to complete this tool? What would facilitate this process?</td>
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<td>Design Quality and Packaging: Perceived excellence in how intervention is bundled, presented, and assembled (CFIR).</td>
<td>10. Do you have any initial reactions to the tool? 11. Were there certain things that you liked or disliked about the tool? 12. Is there anything you would add or change about the tool?</td>
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REFERENCES


