

Bridging Community, History, and Culture in Personal Informatics Tools: Insights from an Existing Community-Based Heart Health Intervention for Black Americans

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A healthy diet and increased physical activity are essential for reducing the prevalence of cardiovascular disease and related deaths, a worldwide public health concern that disproportionately affects Black American communities. Still, Black Americans can face unique challenges meeting dietary and physical activity requirements due to inequities in access and quality of care, environmental and local factors, and difficulties in changing individual health behaviors. Personal informatics and self-tracking tools are one way of increasing awareness of health behaviors to motivate behavior change. However, there are still gaps in knowledge about what encourages different users to engage with personal informatics tools over time, particularly when used in collaborative, community-health settings. This paper contributes a nuanced understanding of fifteen participants' reasons for engaging in an existing community-based health education and behavior change program that combines collaborative self-tracking with culturally relevant content and social engagement to motivate heart-healthy behaviors. We illustrate participants' positive and negative experiences engaging in self-tracking and collaborative tasks during the program. We also discuss how participants envision integrating technology might support and hinder participant engagement and the work of deploying community-based, public health interventions. Finally, we discuss design implications for culturally informed, community-based personal informatics tools that engage Black American's in heart-healthy activities.

CCS Concepts: • **Human-centered computing** → **Empirical studies in HCI**; • **Applied computing** → **Health informatics**; **Health care information systems**.

Additional Key Words and Phrases: personal informatics, culturally-informed design, community-based design, collaborative tracking

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1 INTRODUCTION

Personal health informatics tools are often one approach used to support and motivate healthy behaviors [36]. These tools can be potentially beneficial for goal setting and self-reflection, which can be helpful in making the gradual changes necessary to prevent and manage a chronic illness [26, 37, 42, 46, 56, 76]. For example, a healthy diet and increased physical activity are often essential for reducing the prevalence of cardiovascular disease and related deaths, a worldwide public health concern that disproportionately affects Black communities. Black Americans can face unique challenges meeting the dietary and physical activity requirements needed to prevent and manage disease due to inequities in access and quality of care and environmental and local factors [50], but also because of difficulties in

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changing individual behaviors [4]. While it is often not feasible for HCI researchers to examine the effect of these tools on long-term behavior change [36], designing personal informatics tools that are engaging and effective can be essential for encouraging participation in activities that lead to better health outcomes over time. However, there are still gaps in understanding of what features of personal informatics tools can foster the engagement [10, 19, 27] needed to motivate their use among specific groups, particularly in community-based settings.

This paper explores participants' experiences in an existing community-based health education and behavior change program to reduce heart health risks in Black communities. The nearly 20-year-old program uses a comprehensive set of tailored educational and programmatic activities to motivate heart-healthy behaviors. One activity uses culturally relevant content to engage members in non-digital, collaborative personal informatics tracking (e.g., step and food tracking) and has been effective over the years at reducing heart health risk among its participants [59]. We engaged fifteen former program participants in online questionnaire interviews using email and telephone [32] to insights into: (1) what facilitates their engagement in the program, (2) what they felt were barriers and open challenges, and (3) how they envision technology could support or hinder the program in the future. We aimed to understand considerations and implications for designing community-based culturally relevant personal tracking tools that leverage technology to support similar populations of users.

We found that the known effectiveness of the program for integrating education and support, community-building activities, and the use of historical stories that garnered personal and spiritual connections were key features that motivated participants to engage in the intervention. Despite this, participants also discussed challenges coordinating, connecting, and growing the community and felt that technology could help reduce individual tracking burdens and support community building and program evaluation efforts. Our findings also highlight potential design tensions [72] raising concerns about the implications technology might have on reducing offline community and social activities. We discuss the design implications for personal informatics tools that support community-based health programs, including designing for share experiences, enhancing offline community, and health workers and public health advocates. Our findings contribute a better understanding of how we might design collaborative personal informatics tools that support tailored, community-based health interventions.

2 RELATED WORK

We discuss the role of personal informatics tools for promoting healthy behaviors, the role of collaboration and social support, and the importance of integrating cultural relevance in the design of health informatics tools.

2.1 Digital Personal Informatics Tools for Promoting Healthy Behaviors

Researchers have long studied the use of personal informatics [61] and self-tracking tools for promoting healthy behaviors and behavior change. Personal informatics is the act of collecting data about oneself for monitoring or reflection [15, 16, 39]. Thus, personal informatics has been around for years and includes manually tracking approaches that use paper and pen and automated digital solutions. Researchers have examined the practice of personal informatics, creating models that provide insight into how self-tracking leads to individual goals. For example, Li and colleagues introduce the staged-based model suggesting five stages (preparation, collection, integration, reflection, and action) that individuals experience when engaging in self-tracking for self-knowledge [38]. Rooksby and colleagues present different styles of self-tracking, including reaching goals, documenting, diagnosing, collecting rewards, or because of pure interest in technology [63]. Epstein and colleagues introduce another model that emphasizes the cyclic process of tracking where there are ongoing processes of collection, integration, and reflection and where lapsing may be resumed

[22]. These models apply to self-tracking broadly but have helped highlight the different tracking practices and the associated open challenges in each phase.

The increased availability of digital personal tracking tools and sensor-based technologies has led to more tools that support personal health informatics practices. Digital personal informatics tools are often thought to ease health-related self-tracking efforts by automating tracking efforts or improving awareness and engagement with tracked data [27]. Digital personal informatics tools have been developed to support self-tracking of physical activity [11, 12, 29, 65, 66], pregnancy and menstrual health [21], mental health [34], eating practices [25, 40], and sleep [7], among others. Digital tracking tools have also been developed to support disease, and chronic illness management [26, 37, 42, 46, 56, 76]. For example, MacLeod and colleagues found that there are similarities but also differences in tracking practices among those with chronic illness, noting the need to consider nuances in types of chronic illness [42]. Vizer and colleagues discuss the differences in self-tracking for chronic illness management when developing illness-related tracking tools highlighting the unique challenges of ongoing tracking and social components over time [76]. However, some researchers have also found that while technologies can ease some of the burdens of self-tracking, they do not always lead to better engagement or better uptake of the tools [10, 19]. For example, Clawson and colleagues found that while some users abandon fitness trackers for positive reasons such as meeting their goals or upgrading a device, many also abandoned the tools for negative reasons such as a mismatch in expectations, technology complexity, or failure [10]. Epstein and colleagues found that individuals abandoned personal informatics technologies because they find tracking difficult, are not comfortable with the information revealed, or have data quality concerns, among others [19]. However, they also found that users expressed a myriad of feelings about their decision to abandon, ranging from no effect or freedom to guilt and frustration after tracking. Because of the challenges of tracking and the consequences of abandonment, Gulotta and colleagues suggest a need to better understand and implement strategies that would foster better engagements with personal informatics tools [27].

2.2 Collaborative and Social Support in Personal Health Informatics Tools

One way that researchers have explored fostering engagement in personal informatics tools is through social and collaborative tracking [20, 23, 41, 60]. As reflection is often an essential component of personal informatics practices [8, 11, 16, 18], one approach has examined how to support collaborative reflection and sensemaking of tracked data [23]. Feustel examined participants' preferences for engaging with cohort data and how they integrated the data into their self-reflection processes [23, 60]. However, apart from the collaborative data reflection, others have explored how social sharing and other social tasks impact users' experiences with personal health informatics tools.

Several researchers have studied the implications of sharing self-tracking health tools using social media. Chung and colleagues, for example, explored the social benefits experienced by a group of users that used Instagram to share their food choices [9]. They found that participants saw sharing as a way to support themselves and others wishing to engage in better eating habits. Others have done similar studies examining the benefits and barriers of using social media for supporting health-related self-tracking, such as [9, 20, 33]. Murane and colleagues studying personal informatics for mental health found that collaborative or "co-tracking" efforts could take several forms, including one in which another individual would capture the personal data of another when they were not able to do so [51]. These studies highlight the benefits and limitations of social and collaborative tracking as well as participants' concerns. Another set of studies have examined the deliberate inclusion of social engagement within personal health informatics applications. Saksono and colleagues have examined the use of social rewards such as stories for engaging low socio-economic status families in physical activity tracking [64, 66]. Similarly, Grimes and colleagues explored shared stories as a way of engaging

African-American families in healthy eating [25]. Unlike the previously discussed work, these studies have examined the intentional inclusion of social features on participants' engagement with personal informatics tools.

2.3 Culturally Informed Design and Digital Health Tools

Another way that researchers have explored fostering engagement in health tools more broadly is through culturally relevant design. Researchers that examine health disparities often look at socio-demographic factors such as race, sexual identity, gender, socio-economic status, and their effect on disease prevention and management and health outcomes [58]. Because of the known effects that demographics can have on health outcomes, some health technology design researchers also advocate for exploring culturally-informed approaches for better engaging different populations [2, 48, 49]. Benda and colleagues note that not considering inclusivity in the design of healthcare technologies can introduce harms beyond use or non-use [2]. They discuss these harms as intervention-generated inequities where an intervention that aims to improve equity falls short and ends up benefiting advantaged compared to disadvantaged groups. Based on a systematic review of literature of health technologies use in historically underserved populations, Montague and Perchonok posit that while these technologies offer opportunities for positively impact health in those populations, the technologies must be tailored to the population to increase the likelihood of behavior change[48]. More and more, the same type of tailoring is being studied in the design of digital personal informatics and other mhealth tools [25, 43, 52–54, 71].

Grimes and colleagues, as part of their work with low-income African-American communities, highlight the importance of designing “deeply local” applications [25]. In their paper, they share that participants felt encouraged that others were “concerned about African-American health”. Harrington and colleagues also note the importance of understanding the broader socio-technical context of participants they brought together around discussions of designing health technologies [28]. In their work with Native American youth, Vigil-Hayes and colleagues found the need to consider nuances in perspectives even between different tribes because of cultural differences [75]. Studies have similarly found that understanding cultural and cultural relevance is key for designing appropriate and accepted health applications in other contexts [43, 52–54, 71]. In this paper, we explore the motivators and challenges of participants in an existing community-based health education and behavior change program that uses personal informatics, collaborative, and culturally-informed design to motivate heart-healthy behaviors among participants. This paper builds on prior work on personal informatics tools and the use of socially and culturally-informed design for inspiring behavior change by highlighting aspects of the program that fostered engagement, potential areas of improvement, and areas where technology might support or hinder the program's efforts in the community.

3 BACKGROUND: COMMUNITY-BASED PROGRAMS TO SUPPORT HEART HEALTH

Community-based and other population-based health interventions have a longstanding history of use in public health and health promotion for improving health behaviors [45]. Framed by ecological models, community-based interventions rest on the premise that individual behaviors are influenced by the social environment, including at organizational, community, and policy levels [45]. Community-based research in public health, therefore, often emphasizes active community member involvement through close and strategic partnerships between members, organizations, and researchers to address different levels of inequity that lead to disparities in the community [31].

3.1 Supporting Heart Health in Black Communities

Many of the first community-based interventions focused on reducing cardiovascular disease (CVD) risk; however, many early programs did not involve or test interventions among those who are today most at risk for CVD risk [70]. Instead, most programs focused on Caucasian, middle-class, educated populations limiting the involvement of other populations that had higher risks of disease [70]. However, over time researchers began to find that certain groups such as African Americans face unique challenges to addressing CVD risks requiring a tailored approach [70]. For example, racial disparities, including access to care, treatment adherence, and health outcomes, are more prevalent in the African-American community [70]. Many African-Americans have limited access to effective heart disease prevention programs despite being at higher risk. African-Americans tend to live in environments that promote higher-risk behaviors, have a higher risk of hypertension (i.e., high blood pressure), and higher incidence of adverse outcomes due to hypertension (e.g., stroke, ischemic heart disease) [70]. Research has also found racial disparities in adherence to treatment such as regular blood pressure checks and medication and disparities in access to care critical to preventing, managing, and treating heart disease [70]. Further, others have found that historical mistreatment of and discriminatory practices against Black Americans in medicine have also led to mistrust and negative perceptions of the medical community exacerbating efforts to reach some communities [67]. Because of these barriers, some researchers have moved to more localized and tailored interventions that aim to build trust and mobilize the African American communities they serve. In particular, in public health, conducting community-based CVD disparities research has become critical for reducing heart-healthy disparities among high-risk groups [24]. For example, the Jackson Heart Study is one successful community-based observational study that aims to improve heart health among African Americans in Mississippi [69, 73]. The study is conducted in close collaboration with medical institutions, community members, researchers, and historically black colleges and universities (HBCUs) in Mississippi, leveraging those partnerships to conduct research, community outreach, and to train the next generation of multi-disciplinary public health researchers [69, 73]. Similarly, the Charlotte REACH project program emphasized community and policy changes to improve heart-healthy behaviors among African Americans in Charlotte [55]. Each of these programs was tailored to the communities of interest with a specific focus on mobilizing and building trust within the communities to motivate participation.

3.2 The Circle of Friends Walking Program

The Circle of Friends (COF) Walking program is a community-based public health intervention that was designed to reduce heart health disparities in the African American and other marginalized communities that experience high heart disease risk. The COF walking program is one under an umbrella of programs provided by Health Freedom Inc., a non-profit in Baltimore, MD. The Circle of Friend program was of particular interest because it is a longstanding (nearly 20 years) success as an evidence-based, community-based heart-healthy program that improves participation in heart-healthy behaviors (e.g., increased physical activity, positive dietary change, smoking cessation) among its participants [59]. COF was also developed by public health researchers who founded the non-profit in close partnership with local community members, including churches and health activists. The program borrows inspiration from those who traveled the Underground Railroad to freedom, incorporating cardiovascular disease (CVD) education and self-management strategies. The program was originally created in 2002 and since that time has been shown effective at reducing CVD risk factors over six weeks [59].

The initial six-week walking program utilizes self-tracking as a tool to engage participants in healthy behaviors. For example, participants track their physical activity and food choices daily and share updates with team members

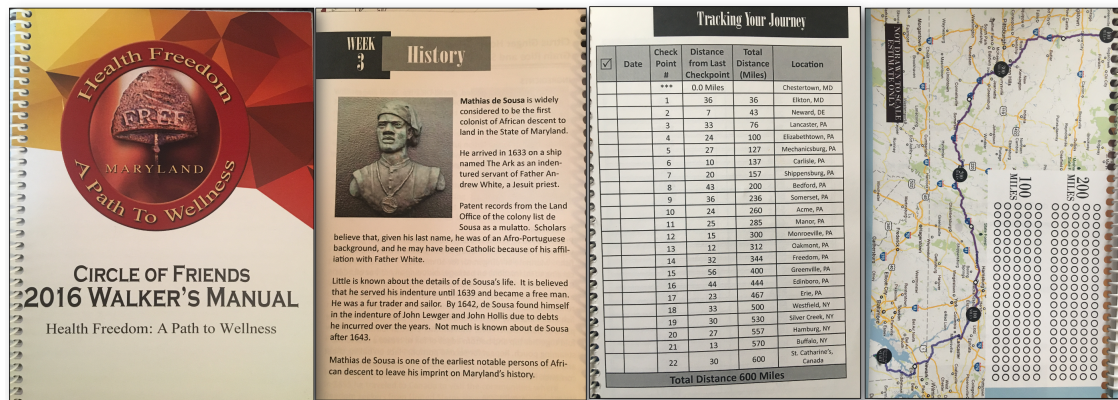


Fig. 1. Examples of participant manual pages including images of tracking tools and the journey map.

Week	Education
1	History of the Underground Railroad; Warming up/Cooling down (stretching)
2	Healthier food substitutions; African Americans in Maryland
3	Ohio's role in the Underground Railroad; Preventing diabetes (steps to lower risk)
4	Presbyterian minister John Rankin (abolitionist); The 8 turns in the road to health
5	Harriet Tubman (abolitionist & political activist); Meal portion control
6	Josiah Henson (abolitionist, writer, & minister); History of soul food
Months 3-12	The Mason Dixon Line; History of soul food (continued); Underground Railroad in New York; Children & nutrition; Recipe for a healthy meal; Black Seminole Indian Scouts and many other topics

Fig. 2. Examples of educational and historical content provided to participants in their program booklet.

and conductors weekly. Conductors also track health metrics such as blood pressure and weight weekly to assist in monitoring health outcomes. However, while the COF program utilizes self-tracking as one of the tools to engage participants, it is not a personal informatics tool alone. The program is also a health education and promotion program that focuses on providing participants with information and resources to maintain healthy behaviors long-term (See Figure 1). Therefore, in addition to focusing on present behavior changes through self-tracking and reflection, participants are also provided with information through the program booklet and resources through their assigned community-health workers (i.e., conductors) that can help them continue to be successful after the programs eventual completion.

In the program, participants attend weekly community peer-group education and fitness sessions led by lay community health workers called “conductors.” Conductors complete training to become qualified in leading participants and instructing them on healthy eating habits and diet-friendly recipes. Participants are encouraged to walk 10,000 steps per day and report their total step count at the end of the week in a paper-based personal health journal throughout the program. Over the six weeks, participants track their distance on a map that outlines the 600-mile journey from Maryland to St. Catherine’s, Canada (See Figure 1), a part of the Underground Railroad. During the initial six weeks and up to the 12 months prior, participants are also provided with history about the Underground Railroad along with educational content that public health researchers developed as motivation to complete their journey to Health Freedom (See Figure 2).

4 METHODS

Three research questions guide this study: (1) What aspects of the current program are beneficial for facilitating engagement and motivating participation?, (2) What aspects of the current program are challenging or need improvement?, and (3) How might integrating technology help or hinder the main goals of the program? We engaged fifteen former program participants that were involved in the initiative in different capacities in online questionnaire interviews using email and telephone [32]. We aimed to gain insights into what facilitated their engagement in the program, identify opportunities for improvement, and identify technology integration’s perceived benefits and concerns. Fifteen participants responded, including conductors that facilitated circles/teams (N=9) for the program, past participants (N=5), directors and staff (N=3), board members (N=2), and advocates/health specialists (N=3). Several participants (N=4) had also been involved in more than one role in the program. Questionnaires were used aligned with prior approaches that make use of email interviews [32] to accommodate participants and provide flexibility. The majority of participants were either 65 years of age or older or 18-35 years of age. Both groups included six participants; however, those 18-35 were most often newer participants. All but one participant (N=5) in the 18-35 age range joined the program in 2019. Interviews were conducted in 2020. Participants’ involvement in the COF program ranged from 1 month to 18 years, with the majority (N=14) being involved for at one year or more.

To accommodate our participants’ schedules, we conducted and administered the questionnaire online, but for those without Internet or technology access, we also provided an option to collect responses over the phone. In phone sessions, the researchers asked questions from the questionnaire and typed responses into the online questionnaire. The questionnaire captured demographic data and information about participants’ experiences in the program, things they enjoyed, and things they felt needed improvement. We also asked their opinion about how they envision technology might benefit or hinder participation in the program based on their past experiences.

4.1 Data Analysis

We analyzed our qualitative data using thematic analysis [14]. Because we used an open-ended questionnaire as a supplement for an interview, we first conducted deductive coding matching questionnaire questions to responses. We then conducted iterative, open coding to identify emerging themes related to participants’ experiences and beliefs about technology integration. Our initial coding efforts results in 26 low level codes of which 2 were merged. Our final coding scheme included four high-level themes related to participants beliefs about (1) what motivated their engagement in the program, (2) what hindered their participation or could be improved in the program, and (3) benefits and (4) concerns did they have about integrating technology in the future. These themes correspond with the sections presented in the findings below.

Table 1. Examples of Weekly Educational Content and Historical Topics

Participant	Age	Years in Program	Role
1	18-35	1 year	Conductor
2	18-35	1 month	Conductor
3	18-35	1 year	Participant
4	18-35	1 year	Conductor
5	65+	1 year	Blood Pressure Management Specialist
6	NR	18 years	Director or Staff Member
7	65+	18 years	Conductor
8	65+	10 years	Participants, Conductor
9	65+	NR	Director or Staff Member
10	51-65	15 years	Conductor, Executive Board Member, Minister of Health, Advocate in Local Church
11	18-35	1 year	Conductor
12	65+	From the Beginning	Participant, Conductor, Executive Board Member, Director or Staff Member, Volunteer Coordinator
13	65+	10 years	Participant, Advocate in Community Health Fairs
14	36-50	13 years	Participant
15	18-35	1 year	Conductor

5 FINDINGS

The findings presented below correspond with the four high-level themes from our data analysis. Themes focused on participants' perceptions of the existing non-digital programs' benefits (what engaged them), opportunities for improvement, and the ways they envisioned technology might help or hinder program efforts in the future.

5.1 Benefits of the Program: What Motivated Engagement?

We found that all participants felt the program was beneficial in its current state because of its long-standing history of success improving its members' health outcomes. Participants attributed the program's success to the close integration of intervention, education, and actionable support provided through the initial six-week program. However, in addition to blending key components of intervention and support, participants also felt that the program's structure, which fostered community building through shared knowledge and experiences and use of historical context, helped them stay engaged during the six weeks.

5.1.1 Improving Health Outcomes through Intervention, Education, and Actionable Support. Participants shared that one of the main benefits of the current six-week program was its known track record of improving heart-healthy behaviors among those who participated within the community. Participants thus felt that the known effectiveness of the program was vital to their initial decision to participate. One of the participants who in the past had also served as a blood pressure specialist for the program said the thing she liked most about the program was, "We have actually saved lives," noting the program's track record for improving healthy heart behaviors but also reducing risk factors for developing cardiovascular disease. However, beyond initial perceptions and the programs' focus on reducing risks, participants commented that they also appreciated that the program improved their access to information about how to live heart-healthy lifestyles and resources in the community that could help them improve their health and wellness

over time. P3 shared, “The amount of health and wellness information and the effort to track progress helps to make the program comprehensive and an even greater effort to promote the benefits of health and wellness.” Another participant, P12, who had been involved in different roles in the program, shared that they felt that the program also helped them become more aware of potential health issues. P12 commented, “[It is] a way people find out about health problems”. Many of the program participants were interested in improving their health or the health of others in the community, however some did express that it could be challenging to find the information and resources to maintain and manage their health and other discussed that some may not be aware of where to look. The fact that the program provided intervention and education, and resources were seen as a benefit. Because the information and resources were integrated as part of the program’s structure, including actionable support, some participants felt it made it easier to put what they learned to practice.

5.1.2 Building Community Through Shared Collective Knowledge and Experiences. In addition to health-related benefits, participants commented that in being a part of the program, they felt they were part of a collective group on a similar journey and having that social support was a good motivator. The program was designed to support these interactions, promoting smaller group meetings led by a community health worker serving as facilitators. P6 shared that they felt supporting others and engaging the community were two benefits of the program that kept them motivated throughout their time in the program. They commented that “support of others, engaging the community, sharing history, helping others learn our [the African American community’s] history” were important to the experience. Other participants also discussed that the built-in social support and the programs’ focus on tracking progress were key motivateteam-buildingletting tasks associated with the program. P4 commented, “ Weekly check-ins to record total steps taken during the previous 7 days was helpful and motivational to get me to move during the week”. P11 shared that as a conductor, the connection and support received were an important element for helping individuals in their circles meet individual goals and their circles for reaching goals as a team. They stated, “networking and team building [was important] to reach a collective and individualized goal of a healthy weight and lifestyle”. Therefore, we found that the social components and community building activities and tracking were essential for motivating participants to make changes to improve health. For CHWs, these program components helped them also inspire and bring together the team for collective action, and individuals felt that the community-based approach made their participation more manageable and more engaging.

5.1.3 Using Stories of the Past to Motivate Healthy Futures. Participants also valued the historical, cultural, and spiritual facets integrated into the program and that the program also presented an opportunity to learn about African-American history. P3 shared, “The key benefits are that health and wellness are being promoted through a program that inspires determination through a spiritual purpose and also builds a community and support system that serves as mutual motivation for all its participants.” Many participants remarked on the historical and spiritual aspects of the programming. P1 noted a benefit of the current program was that it was a “tailored program offering more than just health benefits”. This participant like others believed that including culturally relevant and historical content relevant to the African-American made the program more meaningful. For example, P2 shared, “ I believe having a meaningful spiritual and historical connection to health and fitness is the main benefit of COF.” P15 shared that they thought that the program was, “a unique and spiritual way to motivate Marylanders to improve their overall health. It incorporates African American history into a fitness program.”

Participants also felt that including the culturally-relevant content helped them to become more engaged when participating in the program. P4 commented, “The historical aspect of the program is a thoughtful way to keep me

engaged.” Apart from individual benefits, participants also discussed that they felt the program led to new learning opportunities for their families. P8 noted that they felt the benefits of the program were, “[a] focus on personal health and to share with family, learning about the history of Baltimore, MD and African Americans, being informed of health and nutrition activities, and making new friends”. Therefore, when discussing the program’s key benefits, participants often linked the program’s emphasis on health outcomes, community, and historical and spiritual contexts as key motivators and reasons for their participation in the program.

5.2 Opportunities for Improvement: What Hindered Participation?

While the participants appreciated the program’s effectiveness and community-based approach, participants did note challenges partly due to the logistics of coordinating group activities, building new community ties, and struggles with individual motivation.

5.2.1 Coordinating Busy Schedules. One challenge participants discussed revolved around effective scheduling. To facilitate the program within a community, CHWs have to coordinate with their group members (i.e., circles) to find a location and schedule weekly meetings. Weekly meetings were not only associated with community-building, as discussed previously but also played a key role in data collection efforts that help monitor the program’s effectiveness over time. Therefore in addition to allowing members to report progress and socialize with other participants, weekly meetings provided a common time for CHWs to collect key health information (e.g., blood pressure, weight) needed to gauge their group’s progress as well as to connect participants with resources to help them on their journey. However, both participants and conductors found it challenging to coordinate and schedule these sessions. P3 commented, “It might be hard to find a consistent time and place to hold these sessions [weekly meetings].” Several other participants mentioned that coordinating and finding places to meet weekly was difficult for them amid busy schedules. P11 noted a key challenge was “Having to reach a common time and location to meet”. Similarly, P8 stated one of the major challenges of the current program was, “Busy schedules ... unable to meet as a group”. Deciding on meeting logistics was complicated because for the program, most scheduling was being coordinated manually by the CHW, who may have other responsibilities apart from their support of the program. Using smaller groups coordinated by CHWs allowed for more flexibility in scheduling as most CHWs were familiar with the people in the groups they led because they were part of the communities before the program began. However, this also came with the challenge of coordinating and managing individuals often with different experiences, access, and schedules.

5.2.2 Keeping Connected and Sustaining Individual Motivation Between Meetings. Related to coordinating challenges, because weekly meetings served as the primary touchpoint for CHWs and participants, several participants discussed that it could be challenging to sustain their motivation over time due to daily challenges. For example, P4 commented that although they found the program mostly beneficial, but one challenge was, “I feel that while there were educational segments on how to improve your nutrition, but [I] did not ultimately practice or incorporate the lessons into my everyday life”. The program provides a comprehensive set of tools to assist participants with improving their heart health, but we learned that some components were more integrated than others. Both P1 and P3 shared that they found it challenging to remain committed and motivated at times, and P1 noted that “Life changes [sometimes] affect capability”.

Another related challenge participants discussed was staying connected to team members between meetings. P13 suggested that some of the challenges they encountered were due to difficulties staying connected with other team

members. They shared, “It was difficult to] stay dedicated and continue to reach out to others”. We found that CHWs used different methods for connecting with participants between meetings, but they faced similar challenges of scheduling and busy schedules that made it difficult to connect with people in their circles. Participants also noted that connecting with other team members during the week could be challenging, especially if they did not have a preexisting relationship with other participants.

5.2.3 Building Inter-generational Ties and Growing Community. In addition to existing challenges experienced by CHWs and team members, participants also mentioned difficulties recruiting beyond their typical participant base. The majority of participants in the current program were 55 years of age or older. While not a significant problem for the program itself, the program did want to broaden its community base to younger participants. Preventive heart-healthy behaviors learned earlier in life can lead to better health outcomes later in life, especially in underserved communities where heart disease presents more often at earlier ages [5]. As a community-based intervention for heart health, the program wanted to reach younger audiences not only for community-building purposes but to involve individuals earlier to prevent the development of heart disease. For example, according to the Centers for Disease Control, African-Americans that are age 18-49 are two times more likely to die from heart disease than whites, are more commonly living with chronic illness at younger ages, and are more likely to die at an early age from chronic illness [5]. Thus, the earlier an individual engages in heart-healthy practices, barring hereditary factors, the more likely they are to reduce their risks. Several participants, particularly those who served in leadership roles (directors, staff, advocates, and CHWs), felt it was imperative to understand how to attract a younger audience. While our sample included a good representation of younger participants, we learned that reaching younger populations had been difficult and was a key concern. P6, a staff member, noted that it had been challenging “getting younger people and men involved” in the program. One potential reason for this disparity was due to practical limitations. As a community-based health intervention, the program relied heavily on community members to become involved and lead the program efforts with the support of the program staff. However, participants in different roles mentioned that recruiting volunteers was challenging. The program also wanted to expand its reach to include more underserved communities, but P4 mentioned that “trying to reach larger groups in underserved communities” was also a challenge. P12 echoed this concern noting that “getting people to become a part [of the program]” had been difficult over the years. Therefore, while participants did not share specific reasons why they believed the recruitment to be challenging, they felt it was a challenge that needed to be addressed in any future version of the program.

5.3 Envisioning a Future with Technology: How Might Technology Improve the Program?

Reflecting on their experiences and what they felt were the benefits and challenges of the existing program, we asked participants to envision how they believe integrating technology into the programs’ design might help or hinder efforts. We found that participants felt that there were several opportunities where a technology intervention might better support individual and collaborative, tracking efforts and support better coordination and information dissemination among smaller groups. They also felt that introducing technology might also help improve recruitment and provide opportunities to scale the program to others interested in participating but may have less flexibility in their schedule to meet in person. At a logistical level, participants in leadership roles envisioned that technology could help support thought data collection efforts needed to examine the programs’ effectiveness over time. Despite this, participants

also raised that a move to technology might limit participation among some existing participants due to digital literacy, access limitations, or preference.

5.3.1 Improving Program Experience for Participants and CHWs. Participants felt that integrating technology into a future design of the program could significantly reduce tracking efforts leading to a better user experience. P2 noted that supporting efficient tracking of steps and food is often used in other health programs and felt that it would improve the user experience for this program. They stated, “Apps like Under Armour have a built-in inventory of food and their calories that people can log in how much they eat and keep track of their calories. A similar thing could be used for this app. Also, I would add in a built-in step-counter.” Participants shared that one of the challenges of the current program was that all tracking and associated calculations were done manually, and they felt that using built-in trackers could make the process easier and more efficient. Several participants noted that they thought that technology could be used to reduce tracking efforts especially related to step counts and food. P3 said that integrating technology could alleviate quite a few of the current challenges associated with manual tracking and make overall participation more enjoyable. P3 shared, “I feel that it [technology] would greatly improve the program and make it a more robust and more fun, comprehensive experience. Translating it into an app might facilitate things and make it more convenient as opposed to manually organizing and tracking things.” As mentioned previously, the current programs used a manual tracking approach where participants tracked their steps or the time they exercised and used these numbers to identify the number of miles traveled on the Underground Railroad. In collaboration with community members, the programs’ creators and volunteers manually walked the trails on the map to create a custom calculation and conversation chart to convert steps and time exercised to miles. At the same time, they researched the history corresponding to landmarks highlighted on the route. Because of this, even with an automated step counter, participants would need to convert their steps taken or time exercised to miles using the custom calculation. Only then could they see their progress traveling the Underground Railroad. Thus, while digital tracking tools or technologies could help participants manually track steps, exercise, or foods, they were currently not integrated into the core program and were not required to participate. Because there were no special tools required for participation, it allowed for more inclusivity, but some participants also discussed an area in which technology might improve. For example, P4 suggested as a technology improvement, “Create a map of the 600-mile-long trip that fills in your weekly steps and shows how far you have walked” suggesting that in addition to individual step tracking efforts, participants also felt that technology could also help improve the experience of the virtual walk.

However, beyond individual tracking efforts, participants also saw technology as a way to ease some of the challenges of coordinating teams during weekly meetings and throughout the week. Participants mentioned that it could be challenging to coordinate weekly meetups, which served both social and practical purposes. During meetings, participants were able to share their progress and provide encouragement to their circles, building on the programs’ goal of fostering a community and shared experiences among participants. In addition to encouraging and inspiring their teams, CHWs were also able to collect the data needed to access participants’ progress, provide information and resources to their team members, and collect the data required to evaluate the program’s long-term effects on health outcomes. However, currently as mentioned by participants coordinating these efforts could be cumbersome. Some participants noted in their responses that due to challenges coordinating, they sometimes could not attend weekly meetings. However, participants shared that they felt technology could also be better leveraged to help them better connect with members of their circle. P3 noted that in addition to streamlining the experience, they felt that technology could help improve communications among circles between weekly check-in meetings. P3 shared, “Technology would help put everything in one place—from supplying health information, to the automatic tracking of steps, an algorithm

to cater towards one health goal, and training videos/instructions, these would all elevate the program to the next level. To have this all in one place and to provide a place to communicate with everyone in one's Circle of Friends, it will make the program easier and more involved and helpful." CHWs also shared this vision of technology supporting the program noting as P1 shared that they believed technology could be used to help "lessen conductor work" overall. Aligned with participant vision of improving social interactions between meetings, P8 who had been both a participant and conductor suggested that one potential improvement they would like to see is that they, "would like people to be able to connect even when they aren't able to attend meetings". P8 also shared that they felt technology could help "keep track of activities and nutrition" and as a conductor, it could help "keep track of participants and categories of exercise [as well as] historical data [about participants]". Other CHWs also noted that they felt that technology could also support them as team leaders to manage and coordinate individuals and teams as well as the data they collect in support of the program evaluation efforts over time. P15, another past conductor, shared that they felt technology could most benefit "logging miles, sharing healthy recipes, and building a group message to keep group members motivated." Aligned with the views of other CHWs that participated, they felt that integrating technology could not only support participants but CHWs in their coordination efforts particularly in facilitating social interactions and community building. P7, another past conductor, shared they felt in the long term "It [technology] would be needed to keep a going record of information. First of all I think it's [technology] needed. Think it's a great idea." In this quote P7 is referring to the data collection efforts that the CHWs engage in to support participants throughout the program and their support of the larger efforts to evaluate the program as an effective public health intervention.

5.3.2 Supporting Data Collection and Exchange. Another area where participants felt technology could support the program was building sustainable practices to support the program's evaluation. Participants envisioned having the ability to maintain program-based data collection efforts and scale the program beyond the current locale and demographic. As noted by CHWs, one aspect they felt technology could address is improving data collection efforts for program-level evaluation. As a public health intervention, it is key that the program continuously evaluate participants' health outcomes to determine its effect on heart healthy behaviors and risks. Therefore, CHWs are formally trained not only to facilitate groups but to also collect health metrics needed for program level evaluation. P4 a past CHW shared that they felt technology integration could help with that aspect of the program as well. They noted, "It [integrating technology] could help with improving data collection for program evaluation and research purposes." Another conductor, P11 shared similar sentiments. They shared, "Technology will allow the program to be portable, and reach more people outside of those in your group. It will also make data collection more efficient." However, beyond assistance with collecting and managing data, participants also felt technology could help broaden the programs' reach within the current community but also nationally.

As discussed previously, participants shared that while the program had been shown effective, they sometimes struggled to recruit beyond their current demographic. Most participants were older adults (55 and older) and identified as women. However, improving heart health and health disparities in communities requires preventive interventions that span the entire generational spectrum. Therefore, past participants, conductors, and program staff envisioned that technology might be a vehicle to get more younger participants involved (54 and younger). P6 shared that they felt that technology could benefit the program for just that reason. P6 felt, "[a benefit of technology would be to] help attract younger people and expand the reach of Health Freedom." P6 shared that similar to other participants' technology could simplify program interactions by later stating, "that [integrating technology] would be great, especially the walking map. It would be easier and always with me. Have the manual on an app with the walking sites, showing the local history

and offer different routes.” P14 shared that they felt technology could expand reach even between members of the same family noting, “technology may make information more accessible and interactive to individuals/families; participation may increase.” P15 shared that including a technology component in of itself might appeal to younger populations sharing their belief that “I think it would be great in this new age of technology. Most people have smartphones. It will also appeal to younger adults.” However, others believe it could also help to scale beyond the current locale. P10 shared that they envisioned technology could not only help recruit new sites but also retain those sites noting that they felt technology would be beneficial for “recruiting new sites as well as changing the program to encourage and retain new sites.” P14 noted that it had been challenging “ trying to reach larger groups in underserved communities.” Therefore, participants overall shared enthusiasm for including technology to improve the program’s individual and team experiences and for supporting sustainability of the program as a public health intervention over time.

5.4 Concerns About Integrating Technology: How Might Technology Hinder the Program?

Despite the enthusiasm for integrating technology into the program, there were also genuine concerns about how technology might disenfranchise some participants and alter the program’s strengths, especially the sense of community participants felt the program builds through stories of history and spirituality. Participants discussed three concerns where they felt we would need to carefully consider as we moved forward with any technology integration efforts: (1) disenfranchising the existing participant base, (2) making participation more difficult and (3) reducing community building and sense of community

5.4.1 Disenfranchising the Existing Participant Base. Given that the current program did not require any special tools to participate beyond the paper manual, some participants raised concerns that a move to a fully digital intervention, might disenfranchise some existing participants. In particular, they raised concerns about disenfranchising participants with limited digital literacy and those who did not have access to technology in their homes. P11, a past conductor, shared that some participants might not have the digital literacy needed to participate in a fully digital intervention and shared, “I would like this a lot. It would be very convenient for my lifestyle ... My only concern is for individuals who are not technology-savvy. I would not want to exclude them from participating because of the new format of the program.” Other participants raised similar concerns suggesting that given the existing participant base, there may be challenges. P1, a past conductor, shared that based on their experience, integrating technology “would be helpful for a younger person but [you] might have issues with an older person”. P15 also raised concerns that they felt using “it [technology] might be difficult for elderly adults.” Concerns about disenfranchising individuals with limited or no digital literacy and without tech access were common concerns. P14 and P1 both noted that whatever technology we developed it would need to ensure simplicity. P14 suggested whatever we created was important that we , “keep it as simplified and user-friendly as possible” and P1 simply suggested, “simpler is generally better.” However, participants’ concerns seemed to focus beyond usability to also not overly complicating participation for those that choose not to use technology.

5.4.2 Making Participation More Difficult. Some participants raised concerns that technology if not appropriately integrated could also make it more difficult for people to participate, and that would directly contradict the broader public health goals of the program - bringing equitable heart health interventions to under-served communities and marginalized individuals. The program was designed to be inclusive; therefore individuals with a traditional pedometer could participate alongside those with step-counting apps or devices and those with no pedometer at all (i.e., manual

trackers). Thus, participants emphasized that there should be alternatives for those that find using technology difficult. P14 mentioned, “not everyone may or can use an app if they have limited access to apps other alternatives should also be explored as well.” P10 shared that they felt, “Use of social media and technology will increase younger persons to participate definitely. But it may not assist other generations, so a mixture of old new will be essential.” P3 suggested that we may therefore also need to include some built-in support or look at hybrid solutions for those that are less familiar or choose not to use technology. They shared, “It might be difficult to attract an older crowd to the technology, there should be a dedicated session to train them to use the app, and from there they can choose whether to use the app or not.”

5.4.3 Reducing Community Building Efforts and Sense of Community. Related, participants also shared concerns about how introducing technology might reduce community building, social activities, and the sense of community that comes along with meeting in person. While they were enthusiastic about the potential of technology for promoting socialization and community between weekly meetings, they were also concerned that too much technology could reduce the benefits they felt came with meeting in person. As discussed earlier, participants appreciated the community-building activities built into the program, including the use of historical stories of the Underground Railroad to motivate behavior change and bolster the spiritual ties and the opportunity to build community with a shared purpose. Participants felt that technology could enhance existing activities in one way, but did not want it to take away from the existing in person activities built into the program. P11 shared, “I am also concerned if the app-based approach will hinder social networking opportunities between participants”. P11 also noted concerns that reducing the availability of alternative methods might reduce these opportunities for those without technology access.

6 DISCUSSION: SUPPORTING COLLABORATIVE TRACKING IN COMMUNITY-BASED SETTINGS

Our findings highlight participants’ experiences in an existing community-based education and behavior change program that uses personal informatics to motivate better health outcomes. Our findings suggest that participants felt the program effectively brought together people as a community through stories of Black history and culture to build a sense of purpose that motivated individuals toward a common health goal - reducing heart disease risks in their community. It was the program’s ability to collectively integrate community and cultural relevance into an evidence-based heart-health intervention was that participants found most beneficial for motivating participation and keeping them engaged with the content. However, they also felt that there were needed improvements. At the individual level, aligned with findings from prior work [27, 42, 61], participants felt that tracking efforts could be improved by using technology to reduce tracking effort. Participants found the manual tracking approach burdensome and felt that technology could be used to automate some of the existing processes. However, in addition to improving individual tracking efforts, participants suggested how they felt technology could improve social interactions and communications in groups and support CHWs and program staff. Based on our findings, we discuss design implications for future culturally informed community-based personal informatics technologies that aim to improve individual and group health behaviors. In particular, we discuss the importance of history and culture for fostering engagement and community. We also discuss ways technology might be used to better support community-based personal informatics initiatives by enhancing offline community and social support and enhancing the information work of CHWs and other public health advocates.

6.1 Designing for Shared Experiences: Fostering Engagement through History and Culture

Participants in the program appreciated the cultural and historical aspects of the program. Similar to other tools that use culturally-informed design [25, 75], participants saw value in a program that they could relate to personally. Thus our work builds on prior work noting the importance of culturally-informed design for supporting community engagement with health-related technology interventions among diverse individuals. Several participants discussed community building as an essential part of the process of coming together as a group to take the journey to health over the six-week period. Building community through shared collective knowledge and experiences, in this case, a journey to Canada, provided a space for them to discuss their progress and share stories and experiences of their own health and history.

Participants felt that using metaphors to equate the journey of healthy behaviors to the journey to freedom from slavery were motivators for completing their six-week journey. In contrast to other ways stories have been used in personal informatics tools [64, 66], the stories in the program were factual and based on true historical events, which some participants felt provided a way for them to connect with their past spiritually. Other participants felt that it also provided a way for them to learn about their history. Similar to Saksono and colleagues, we found that the use of stories was a key motivator for participants as it promoted bonding experiences [66]. However, differently from this work, the program integrated stories at different levels throughout the program. Not only were they used as reward (i.e., weekly educational content), but as a facilitator of the personal informatics components.

Moreover, while self-tracked data was a key component for sharing in the experience, it did not define the experience. Like prior work, we found that a focus on easing tracking burdens alone was not sufficient [10, 19]. Our participants experienced tracking burdens, but they chose to continue because they felt overall, the experience outweighed the burdens related to tracking mechanics. These findings also align with results from [76] suggesting potential differences in chronic illness-related tracking and the need to consider ongoing tracking and social components. The intervention emphasized building a shared story through participants' engagement in a shared community activity which participants appreciated for engaging in heart-healthy behaviors over time. Therefore, for community-based tracking tools emphasizing other factors such as opportunities to bond [66], shared experiences, culture, or reaching a common goal may help motivate individual users as well as the group. As seen in the existing program, participants continued in the program despite tracking challenges; therefore, focusing on experience might also help compensate for usability and other difficulties associated with tracking. Similarly, while the program has been quite successful in improving behaviors among participants [59], some participants discuss challenges remaining engaged from week to week, therefore in the future, it may be useful to also think about how to support ongoing tracking efforts.

Our findings also highlight that participants believed that one of the most beneficial aspects of the program was that it integrated a shared personal informatics experience with education and resources needed to act (i.e., change behaviors). Self-tracking is a significant component of the program as the data is required to help individuals meet specific goals for physical activity, dietary improvements, and reducing certain health indicators such as high blood pressure and weight. While participants enjoyed engaging in tracking activities, mainly physical activity to complete the map and weekly check-in to build community, participants noted that it was important to have the information and resources available (i.e., education components in the booklet and CHWs) available to help them make changes as needed. Therefore, fostering continued engagement seemed to go beyond personal informatics to other mechanisms that could help take steps to make a change. Participants' sentiments align with longstanding challenges in public health to reach certain communities. Due to factors such as racial disparities in access to treatment and care and other barriers [70], some Black Americans can find it challenging to obtain the information and resources needed to maintain

and manage their health. Participants appreciated that the program provided built-in support through content and access to CHW and program staff to connect them to resources to ease barriers and support their journey. In the future, integrating additional resources beyond reflection that support users in changing behaviors might help foster better long-term engagement among certain groups. For example, this might include integrating educational components on better eating practices or increasing physical activity into the personal informatics tool. Our findings suggest that for some, goal setting and reflection may not be adequate and that helping participants find the resources they need to make the change also needs to be considered.

6.2 Enhancing Offline Community and Social Support

Our data also indicate that while social support was key to fostering engagement in the program, participants believed that technology could improve the experience. In particular, participants discussed how technology could help them better communicate between meetings to promote more social interactions and share progress. They also suggested that they saw it as a way to increase participation by those less represented. While we anticipate other design challenges might emerge by integrating technology, such as the need to investigate how to facilitate shared reflection [23], participants highlighted specific potential design tensions based on their experiences [72] that might emerge from integrating technology. Participants shared their concerns that technology might also negatively impact community-building efforts. Participants discussed the importance of maintaining the social support and community building that occurred in offline interactions. Thus, one approach might be to explore not only ways to help people connect online but also how technology could support offline interactions with individuals and the communities. Grimes discusses the need to consider “deeply local health applications” that allow users to share experiences in their local community [25] and while their examples focus on creating custom categories of food, we argue that this may apply to other personal health informatics features. For example, our findings suggest that offline social support and interactions may be essential for some participants to help build the community needed to sustain even online social interactions. Whereas, our participants also suggested that for some, fully online communities may be sufficient. Murane and colleagues discuss exploring different definitions of “co-tracking” and how other support mechanisms can promote inclusive tracking [51]. Further, tailoring interventions to the individual community is at the core of community-based participatory research in public health [13, 58] and often leads to successful interventions. Thus, we would need to consider ways that technology can support both online and offline communities in the future.

Participants discussed potentially disenfranchising the existing participant base, many of which were older adults highlighting that some may have limited digital literacy and limited access to technology resources. Because of this, some felt that technology might make participation more difficult, and increased online connection might reduce the sense of community they felt help motivate participation. Therefore, in addition to the design implications already discussed, we also reflect on potential design (un)implications [1] or potential cases whether integrating technology might “do more harm than good?” Participants’ concerns are well-founded, given findings that suggest that older adults and younger adults may perceive and use self-tracking technologies differently. Caldeira and Chen, for example, highlight six existing barriers to seniors’ adoption of tracking technologies found in literature [3]. These include, among others, misaligned tracking needs with younger adults [62] for whom these tools are often designed [74]. For example, Caldeira and Chen summarize that compared to younger adults, older adults often focus more on chronic illness management [44], have different attitudes toward tracking technologies [57], and feel their design needs are not considered [68, 74]. One suggestion made is to include a training component to help users that want to engage with technology to do so. The inclusion of such a component aligns with Preussee and colleagues, who suggest that while

older adults perceive self-tracking technologies as useful, training may be needed [57]. However, our findings also indicate that in the future, for communities that have varied access to technology, it may be helpful to consider hybrid approaches which allow participants to engage in the way they find most comfortable and convenient. For example, some are already looking at approaches to better support older adults not familiar with tracking [6]. Some researchers are also exploring strategies for supporting semi-automatic tracking [35] that allow users to customize their tracking experience. However, given the varied access to technologies and the need to integrate data for collaborative tracking, further work would be needed to identify and examine approaches that allow users similar levels of engagement and community when participating in collaborative activities.

6.3 Supporting Community Health Workers and Other Public Health Advocates

Apart from supporting users in tracking and behavior change, our findings also highlight opportunities to support CHWs and other public health advocates. The CHWs that volunteer for the program also collect data on participants (i.e., blood pressure, weight) weekly in addition to the data the participants provide. Currently, this data is collected manually and then is shared with the staff and the program to support long-term evaluation efforts. Because all the data is collected manually, it can be challenging to collect, organize, and manage. CHWs are critical contributors to many existing public health interventions, as they often can as members of the community themselves effectively reach certain populations and can extend access to healthcare resources [17, 47]. Although in the HCID context, some HCI researchers have highlighted a need to better explore ways of supporting CHWs in their practice [30]. In their work with CHWs in India, Ismail and Kumar highlight the need to consider digital literacy, gender expectations and norms regarding technology use, professional expertise, and class difference in technologies that promote power compared to powerlessness among CHWs. Our studies highlight considerations for helping CHWs organize and manage data in the process of providing care (i.e., through providing leadership, support, and engagement in program activities) and in their role in supporting program outcomes. For example, automating some data collection efforts could support CHWs by helping them better identify opportunities for additional support or engagement outside of weekly meetings. However, automating data collection efforts could also ease some of the burdens CHWs face in managing and organizing the data they receive from different participants and sharing their data with program staff. These efforts could in turn help program staff better track participant demographics and health metrics over time to support program evaluation efforts. We believe it will be critical to further explore potential areas for empowerment [30] in consideration of local norms and expectations. Similar to participants' concerns about technology being inappropriately implemented, because of CHWs role in building community among participants, we believe it will also be critical to understand the potential adverse effects of introducing technology on current experiences.

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8 CONCLUSIONS

This paper provides perspectives of participants' experiences engaging in an existing community-based education and behavior change program that used personal informatics, culturally-informed design, and collaborative tracking to motivate heart-healthy behaviors. We discuss what participants found beneficial and challenging and what they felt fostered their engagement in the program over time. We additionally provide insight on how participants believe

technology might benefit and hinder the program in the future. We conclude with a discussion of the implications of our findings for the design of personal informatics tools that support community-based health programs, including considerations of designing for share experiences, enhancing offline communities, and supporting community health workers and public health advocates. Our findings contribute a better understanding of considerations for designing collaborative personal informatics tools that support tailored, community-based health interventions.

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