Original Report: Research Findings

ACHIEVING HEALTH EQUITY WITH E-HEALTHYSTRIDES[©]: PATIENT PERSPECTIVES OF A CONSUMER HEALTH INFORMATION TECHNOLOGY APPLICATION

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Objective: We describe the implementation, clinical outcomes and participant perspectives for e-Healthystrides[®].

Setting: Three independent ambulatory clinics and an historic African American (AA) church.

Participants: Adults with diagnosed diabetes mellitus type 2.

Interventions: e-Healthystrides[®] health coach facilitated intervention

Primary outcome: Acquisition of three new self-management behaviors.

Secondary outcomes: Blood pressure, blood glucose, A1c, attrition rate and participant perspectives of e-Healthystrides[®]

Methods: A convergent parallel mixed method design was used in both pilot studies.

Results: Two hundred and sixty-four participants, aged ~62±16 years, enrolled. Attrition at 52 weeks varied 50%-90% by site. Low engagement users were defined mainly by anxiety with putting health information online. The primary outcome was achieved in 36% of our participants, with the top 3 self-management behaviors acquired being: reducing risk (24.5%); healthy eating (23.7%); and monitoring (16.4%). Problem solving had the lowest rate of achievement (.91%). Blood pressure improved significantly at all sites at 12 weeks and at clinics A,B,C at 52 weeks. Blood glucose improved at 12 weeks: clinic A (P=.0001), B (P=.003), C (P=.001) and D (P=.03); but, at 52 weeks, only clinics A (P = <.0001) and B (P=.0001). Participants felt empowered

INTRODUCTION

Diabetes mellitus, a chronic disease, is ideal for testing e-Healthystrides[®] our health 2.0 consumer health information technology (CHIT). Diabetes mellitus is prevalent, disproportionately affects minority and underserved populations,¹ and accounts for increased morbidity, mortality and health care costs when not effectively managed. Diabetes outcomes depend on effective

by features of e-Healthystrides[®]. Engagement with health coaches and peers was highly valued.

Conclusions: e-Healthystrides[®] is effective for self-management behavior change. Participants showed the best success with healthy coping, healthy eating, and monitoring behaviors. They felt empowered by access to health information and valued interaction with coaches and peers. Our findings support strong relational/social network strategy with a role for coaches as guides (apomediaries) who facilitate skill acquisition using technology. *Ethn Dis.* 2019;29(Suppl 2):393-404; doi:10.18865/ ed.29.S2.393.

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participation by the patient in their own health care. Clinical trials, such as the diabetes prevention program (DPP)² and the United Kingdom Prospective Diabetes Study³ (UKPDS), have demonstrated that physician-directed medical care. while essential, is not sufficient to prevent the complications arising from uncontrolled hyperglycemia.² Additionally, patient-centered а approach to diabetes care is more successful at initiating and

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Address correspondence to Priscilla Pemu, MD, MS; Morehouse School of Medicine, 720 Westview Drive, SW, Atlanta, Georgia 30310; 404.756.6684; pipemu@msm.edu sustaining positive health behaviors than many other patient-physician communication configurations currently in use.⁴ Patients who review and understand the implications of their personal health information are more engaged and successful in their disease management.⁵ Diabetes self-management is a cornerstone of successful diabetes care; yet, successful

We offer a detailed description of the implementation, clinical outcomes and participant perspectives of e-Healthystrides[®] a patient-centered, individually tailored CHIT application that embodies the collaborative ideals of health 2.0.

self-management is challenged by the effort of collecting, organizing, retrieving, interpreting, and acting on inordinate amounts of disease-specific information from multiple sources.

Consumer health informatics (CHITs) applications, as defined by Eysenbach,⁶ hold significant promise for performing these tasks and bridging the gap between clinic care and self-care. The content and individualized feedback delivered through

CHITs can be readily tailored for individual behavior change. When available as mobile applications, CHITs provide accessible, real-time, user-centered information at relatively lower costs,⁷ and is often termed, health 2.0.8 CHITs present an attractive pathway to improve diabetes and other chronic disease care, particularly among high disparity populations such as people of lower socioeconomic status, low health literacy, racial and ethnic minorities, and the elderly.9 The challenge and paradox is that while the uptake of mobile and web-based technologies are rapid and growing, the adoption of CHITs for self-management is relatively slow by both patients and health care professionals^{5,10} and a more pronounced hesitation has been found among minority and underserved populations.¹¹

In order to address this delay in the diffusion of this innovation, we conducted several pilot studies to understand whether: a) patients with diabetes who were served by practices of the Community Physicians' Network (CPN)¹² and a church would accept and use e-Healthystrides[©] to improve selfmanagement skills; b) patients who used e-Healthystrides[©] would attain 3 of 7 self-management skills they had not attained at baseline and persist in the attainment of those goals; c) patients who used e-Healthystrides© would demonstrate improvements in their diabetes outcomes (hemoglobin glucose, blood A1c or blood pressure, attitudes and knowledge; d) identify success factors for use of e-Healthystrides[©] to improve diabetes self-management skills; and

4) a tailored intervention based on individual choices and other dynamic macro cognitive approaches¹³ would impact effectiveness of Diabetes Self-Management Education (DSME).

In this article, we offer a detailed description of the implementation, clinical outcomes and participant perspectives of e-Healthystrides[®] a patient-centered, individually tailored CHIT application that embodies the collaborative ideals of health 2.0.

e-Healthystrides[®] Model and Its Theoretical Basis

We designed a patient-centered, tailored individually CHIT application that incorporates theorybased behavior change constructs from the model of supportive accountability¹⁴ and COM-B system.¹⁵ The COM-B system predicts that interventions that target an individual's Capability (physical psychological), Opportunity or (social or physical) and Motivation (automatic and reflective) can lead to Behavior change. The intervention elements of e-Healthystrides^{©16,17} are education, monitoring with tailored in-the moment feedback, persuasion, modeling, enablement and incentives. These elements directly affect an individual's capability, opportunity and motivation for behavior change. e-Healthystrides[©] involves interaction with health coaches to drive engagement because human factors, such as accountability, bond, and legitimacy, can potentially influence adherence to health 2.0 interventions, especially among minority and underserved populations.¹¹

The model of supportive accountability¹⁴ predicts that adherence to prescribed behaviors will be enhanced when there is human support. In e-Healthystrides[®] this is the health coach. To be effective, coaches are perceived to: 1) be trustworthy and benevolent; 2) have the necessary expertise; 3) frame the relationship as one of reciprocity, through which the patient can expect to receive definable benefits from the coach: 4) involve the patient in the definition of goals and expectations. In the patient-coach relationship, outcomes for which the patient is accountable are clear and tied to larger life goals and values. Expectations are focused on processes rather than outcomes and, negative effects of goal setting, such as inducing perfunctory adherence, are monitored and minimized. Coaches are specific about accountability processes at the beginning of intervention. Performance monitoring is introduced with adequate justification, patient agreement; monitoring is also framed in terms of benefit to the patient and devoid of implied threats of negative consequences. In all these elements, the coach acts as an apomediary.

Participation in e-Healthystrides[®] provided access to the following core features: 1) Personal health record (PHR), ie, the participant's record of medications, weight, blood glucose, blood pressure, diet, and exercise. Participants are guided to create, maintain, and control access to their personal health records using mobile devices (phones, tablets) and computers. The clinical information uploaded directly from home monitoring devices may be accessed by the clinician and authorized project staff with the patient's approval; 2) Self-directed diabetes education. Online access to a self-directed curriculum and quizzes for DSME; 3) Email contact with clinic or health coach. Secure and confidential contact with a health coach; and 4) Peer support. Online social networking through the use of an online discussion forum and remote group discussions facilitated by a health coach.

We hypothesized that when a patient with diabetes engages with e-Healthystrides[®] with the support of a health coach, he or she will improve their self-efficacy for behavior change. This change is mediated through the application of behavioral change techniques (active ingredients), self-monitoring, goal setting, behavioral contracting, problem solving, environmental change/ barrier removal, social support and use of incentives and rewards.

Methods

Design

We utilized a convergent parallel mixed methods design¹⁸ to obtain different but complementary data to answer our research questions. Our rationale for this design was grounded in the need to provide understanding and context regarding the impact of e-Healthystrides[®] on self-management behaviors and health outcomes, which would be missing without the qualitative data. The qualitative and quantitative data were collected concurrently and analyzed separately. Integration occurred during interpretation.

Setting

Three clinics of the Community Physicians' Network¹² and a large church participated in this study; rationale for the choice of clinical sites is detailed in a prior report.¹⁷ The pastor of the church was a member of the Clinical Research Center Community Advisory Board (CAB). The CAB comprises members of the community committed to improving health through community-academic partnerships. Participants for the two pilot studies were recruited from three Community Physicians Network practices¹⁷ (2010-2011) and Big Bethel AME church (2011-2012), a historic African American church in downtown Atlanta with ~3000 members in weekly attendance. With support from the senior pastor, we developed a partnership with the health ministry staff. Lay members of the health ministry were trained and certified as health coaches using American Association of Diabetes Educators (AADE) resources and standards diabetes paraprofessionals. for

Phase I

The study timeline is illustrated in Figure 1. Eligibility criteria for both pilots were similar: diagnosis of type 2 diabetes, according to the International Classification of Diseases version 10; English language fluency; and aged \geq 21 years. Severely mentally incapacitated persons were not eligible for inclusion. Although Internet access at home was not required, a basic familiarity with web browsing was preferred. Access to the e-Healthystrides[®] website was available at computer kiosks at the physician practices



Figure 1. Timeline of study activities CPN, Community Physicians Network.

and the church. Limited access to specific e-Healthystrides[®] website features was available at public libraries.

Recruitment

Recruitment was conducted by: 1) an invitation mailed to all patients identified on the electronic medical record (EMR) as having diabetes; 2) flyers posted in the CPN practices; 3) personal recruitment by clinic staff; and 4) an open 'call to action' from the pulpit by the church pastor during a period of 4 weeks following an introductory visit and discussion by the study team.

Interested individuals were scheduled for the one-day, onsite training and orientation session by project staff. Informed consent was obtained from all participants. The primary incentive offered to patients was their participation in an AADE compliant project, a cash payment of \$25, several self-monitoring devices, and a warm lunch on training day.

Phase 2: Participant Training

Training was delivered in three integrated arms: 1) a oneday training session consisting of interactive presentations and hands-on use of the devices and e-Healthystrides[®] web application; 2) technical assistance calls for ondemand resolution of technical issues; and 3) 11 regularly scheduled study facilitation web conferencing discussions for refresher training in using e-Healthystrides[®] to gather user experience data.

First, participants learned the functionality and capability of the e-Healthystrides[©] web application in support of their ongoing diabetes self-management. Second, selfdirected learning was promoted using the diabetes curriculum and linkages to observe selfmonitored data provided by the e-Healthystrides[©] web application. Third, multiple feedback opportunities were provided for participants to describe and provide suggestions on their experiences with the e-Healthystrides[©] project staff and the virtual community of persons with diabetes. Fourth, several resources for tailored behavioral goal setting were presented and shared.

Finally, participants were guided through using the e-Healthystrides[©] web application as a problem-solving resource accessible on demand.

Each participant was assigned to a health coach. The primary responsibility of the health coach was to support their assigned participants in attaining 3 of 7 AADE self-management behaviors. The health coaches also helped to facilitate web conference calls. Details of the training and coach sessions can be obtained from the lead author.

Health Coaches

The coaches in the clinics were medical assistants nominated based on observation of their attitude and aptitude toward patient education. Coaches in the church were selected from the health ministry volunteers. Training for all coaches consisted of completion of the AADE curriculum for diabetes paraprofessionals.

Data Collection

Quantitative

Participants completed self-administered quantitative questionnaires at baseline, with follow-up at 12 and 52 weeks. The surveys included: the Diabetes Empowerment Scale (DES)¹⁹; Diabetes Knowledge Test (DKT)²⁰; Patient Assessment of Chronic Illness Care (PACIC)²¹; Consumer Health Information Technology survey¹⁷ (CHITs, a locally developed instrument); and the AADE 7.22 Each participant was provided with a sphygmomanometer, glucometer, and pedometer, all of which had a universal serial bus (USB) port to directly interface with

e-HealthyStrides[©] to allow upload of all monitored data onto each participant's Microsoft[®] Healthvault[™] account. Clinical data, such as glycosylated hemoglobin (A1c), were obtained in two ways: electronic health record extract or from individual patient entries based on reports obtained from their physicians.

The two primary methods used to determine e-Healthystrides[®] website usage patterns were: 1) time spent in the application during each log on; and 2) content areas visited by participants over the 12-month period. Twenty-four areas of the website were considered in assessing usage: 11 curriculum modules; 7 options for setting AADE7 behavior and self-care goals; and 6 options for viewing uploaded clinical trend data. Email and the discussion forum were excluded due to technical glitches.

Qualitative

A qualitative exploratory design was used to define participant perspectives on e-Healthystrides[©]. A semi-structured discussion protocol consisting of open-ended questions was used for the focus groups and conference calls. This discussion guide was developed and implemented by co-author (RJW). Clinic and community participants were asked about experiences with e-Healthystrides[©]. Other questions explored symptoms, fears, commendations. concerns, and

Data Analysis

Quantitative variables were summarized using the means and standard deviations or medians where appropriate, while categorical variables were summarized using percentages. Differences between pre- and posttraining/intervention assessments were examined using the paired ttest or Wilcoxon signed-rank test, and McNemar Chi-squared test for categorical variables. The statistical test was two-sided and level of significance set at P≤.05. Kaplan-Meier (K-M) survival analysis was used to plot attrition curves for each study group with participant drop off or attrition from each group as the main event, and time to participant attrition (in weeks) as the survival time. Log-rank test was used to compare differences in overall survivor functions or attrition rates between study groups evaluated at baseline, 12 weeks and 52 weeks, with level of statistical significance set at .05.

Audiotapes of three focus group sessions and 11 conference calls, lasting approximately one-hour, were transcribed verbatim and analyzed. An inductive approach to data analysis, the Constant Comparative Method,^{23,24} was utilized to develop a set of categories that provide a reasonable reconstruction of the data. It provided descriptive or inferential information about the context or setting from which units are derived. Transcripts were read line by line to extract meaningful codes and categories.²⁵ Data coding was conducted using NVivo 10 software. To find common categories across data, focused coding was used.²⁶ Two coders (reviewer) developed categories and themes independently to ensure that the final coding scheme had adequate reliability. Discrepancies were discussed until a consensus was reached.

	Clinic A	Clinic B	Clinic C	Clinic D
n	69	47	30	118
Age years, mean (SD)	65.49(13.81)	58.16(10.2)	62.7(7.9)	62.16(15.2)
Aged >65 years, %	57	25.4	41.3	43.5
Sex (F) %	61.7	73.8	85.5	70.1
		(7.9)		
Hemoglobin A1c %, baseline mean (SD)	8.17(2.12)	6.70(1.10)	7.40(1.37)	8.20 (1.77)
Change in A1c at 12 weeks, %	-2.26	93	+1.18	-1.0
SBP mm Hg, mean (SD)				
Baseline	130.7(21.79)	129.6(20.17)	137.5(20.62)	138.4(25.75)
12 weeks	125.9(16.80)	125.4(16.17)	125.9(18.90)	132.0(18.19)
52 weeks	127.0(13.07)	130.7(12.32)	130.7(16.17)	
P (baseline vs 12 weeks)	.0002	.0058	.002	.02
P (baseline vs 52 weeks)	.0002	.0017	.0017	
Exercise miles walked, mean (SD)				
Baseline	2.14(2.00)	1.69(1.47)	2.21(2.04)	.72(.75)
12 weeks	2.28(1.98)	2.44(2.04)	2.31(2.01)	1.15(.79)
52 weeks	2.55(2.08)	1.40(0.59)	2.33(1.30)	
P (baseline vs 12 weeks)	.69	<.0001	.33	.0003
P (baseline vs 52 weeks)	.633	.278	.198	
Blood glucose mg/dL, mean (SD)				
Baseline	123.3(55.08)	119.1(43.75)	125.19(44.38)	159.92(78.80)
12 weeks	111.7(54.85)	115.3(30.66)	146.8(29.57)	140.45(53.35)
52 weeks	88.2(43.07)	110(19.48)	132(22.56)	
P (baseline vs12 weeks)	.00013	.0029	.0013	.03
P (baseline vs 52 weeks)	<.0001	.0001	.253	

RESULTS

Enrollment and Retention Demographics

A total of 264 participants enrolled from March 2010 through September 2011 from all four enrollment sites (A, B, C, D) (Table 1). The average age of the participants was aged ~62 years. Across the study sites 10%-23% of all individuals who were invited participated in the study.¹⁷ Ten participants formally withdrew from the study during the 52-week period. Attrition at 52 weeks varied between 50% and 90% of initial population across the sites. These differences were significant (P<.0001, Figure 2). Fifteen percent of our participants had less than a

high school diploma; 22.6% held a graduate or professional degree; and 39% had some college or technical/ trade school. Although 82% were comfortable browsing the Internet, only 44% were comfortable putting their health information online.

Website Usage Patterns

Three main application areas routinely accessed were: 1) Goal setting for AADE7 behavior and self-management; 2) trend data for clinical parameters (blood glucose, cholesterol, A1c, blood pressure, weight, exercise); and 3) DSME curriculum modules and related quizzes. In the area of AADE7 goal setting, active users spent the most time viewing and/or selecting AADE7 goals aimed at: reducing risk of complications (t=259 sec); medication adherence (t=251 sec); healthy coping (t=164 sec); and healthy eating (t=163 sec). Figure 3 illustrates average time spent per logon and traffic to view clinical trend data, the DSME curriculum modules, and AADE7 goal setting areas.

We classified participants as active, high-engagement users and low-engagement (LE) users based on time spent in each of the 24 areas of the website. We noted differences in time spent in various areas of the website between active and LE users (Figures 3, 4, 5). LE users spent a maximum of 9 seconds on pages and an average of 6 seconds per logon. These times were well below the time expected to peruse the page content.



Figure 2. Kaplan-Meier attrition curves comparing attrition rates between study groups across time A, Clinic A; B, Clinic B; C, Clinic C; D, Clinic D

Active users showed greater variability in time spent in various areas of the website, which was consistent with the expected user interaction.

Primary Outcome

The primary outcome of three new self-management behaviors was achieved by 36% of our participants. Figure 6 illustrates the AADE 7 self-management behaviors attempted, achieved and attainment rates. The top three are reducing risk (24.15%), healthy eating (23.7%) and monitoring (16%). Table 1 shows clinical outcomes among e-Healthystrides[®] users at baseline, 12 and 52 weeks across all four sites. There were statistically significant improvements in systolic blood pressure, blood glucose and exercise time with some variation between clinics. Hemoglobin A1c was reduced by 2.26 in the best performing clinic and increased by 1.18 in the lowest performing clinic.

Participant Perspectives

The primary themes of empowerment and engagement emerged from qualitative data analysis, with four sub-themes. A few illustrative quotes representing each of the categories are also provided. More detailed quotes can be obtained from the lead author. We coded a total of 137 references.

Overall, participants stated that e-Healthystrides[®] fostered their empowerment through increased awareness of their health status, and actions or behaviors needed to improve their health. They felt positive about e-Healthystrides[®] because it fostered engagement with their peers with diabetes and with health coaches.



Figure 3. Website usage patterns by user type: mean time spent per logon viewing DSME curriculum chapters DSME, diabetes self-management education

Theme 1: Empowerment

Forty-six references (34%) described e-Healthystrides[®] as empowering. "It helped me take control of my own health issues." Of these, 35 references (26%) attributed an increased awareness of their health status and actions or behaviors they needed to take to improve their health to e-Healthystrides[®]. This increased awareness equipped the participants for doctor appointments. Eleven references (8%) highlighted the convenience and benefits of access to their health records and educational material about diabetes.

Theme 2: Engagement

The participants made forty-five references (33%) ento gagement with other diabetic participants and their health coaches as facilitators for their persistence in the study and benefits of their participation. Of these, 24 references (18%) highlighted the value of talking with others with lived experience (apomediaries) in alleviating loneliness and enhancing their knowledge and 21 references (15%) were made about the specific benefits of health coaches included assistance with technology, accountability and inspiration.

DISCUSSION

e-Healthystrides[®] a patient-centered, individually tailored CHIT application, incorporates the collaborative ideals of health 2.0. In our study to assess effectiveness of this application, 85% of the participants were aged \geq 50 years and ~70% were female. Of the participants, 96% self-identified as Black/ African American. A major strength of this work lies in the insights gained regarding ways to enhance engagement with eHealth among our population. The web traffic pat-



Figure 4. Website usage patterns by user type: mean time spent per logon viewing clinical trend data HbA1C, glycosylated hemoglobin

terns highlight our population's interests; we learned that there is great interest in basic diabetes knowledge, prevention, self-management, diabetes resources, complications and medications. Participants were very engaged with reviewing their blood pressure, weight and blood glucose trends, and spent the most time reviewing/setting the AADE 7 goals for: reducing risk of complications; medication adherence; healthy eating; exercising; and losing weight.

The e-Healthystrides[©] intervention led to 36% achievement of three new self-management behaviors as well as a significant, but variable, change in systolic blood pressure, blood glucose, A1c and exercise. This compares well with recent reviews²⁷ that showed A1c reductions in the range of .1%-.8%. Furthermore, the unique insights from our users (often described as difficult-toreach) about the value of peers and

The e-Healthystrides[®] intervention led to 36% achievement of three new self-management behaviors as well as a significant, but variable, change in systolic blood pressure, blood glucose, A1c and exercise. coaches is valuable and novel. This extends the findings from a recent review²⁸ of eHealth applications that relied on tools that assess credibility, ratings online and user engagement measured by application downloads. Low engagement users were significantly different from active users only by their discomfort with putting health information on the internet.²⁹

Our findings are supported by reviews of eHealth approaches to behavior change^{26,28-31} that report improved adherence when an accountability partner is included. Our study has extended understanding of the participant's priorities for engagement with eHealth interventions, especially among minority populations. This is useful as it serves as a basis for developing strategies for





broader implementation. Specifically, it provides an outline of the wishes of participants in eHealth interventions. Strategies that focus on meeting these needs could be applied to the training and certification of health coaches and other providers.

The themes that emerged from this analysis fit very well into a model of supportive accountability,¹⁴ a preexisting theoretical framework that explores how human support enhances adherence to eHealth interventions.

On-going work is focused on piloting the process for embedding this service within an Accountable Care Organization care coordination program for high-risk dual-eligible participants. We should also evaluate methods for assessing the skills of the coaches in the identified domains and relating this to coaching effectiveness. Ultimately, these efforts will lead to the development of successful eHealth approaches for minority patients and thus, to advance health equity and address chronic disease health disparities.

Limitations

In clinical research and community practice, there are often limitations to data collection that must be acknowledged. The study population was a convenience sample, and each patient served as their own control for evaluating the health coaching intervention. The intention to strategically engage community residents who were historically underrepresented in clinical research necessitated the use of a convenience sample. Both the clinic and church partners facilitated this process, as trusted gatekeepers with established relationships (non-research). While a convenience sample traditionally limits generalizability, this sampling strategy was justified for implementation.

The study was launched with the web-based e-Healthystrides[®] application, which synchronized with many devices on the Microsoft[®] Healthvault[™] platform, including blood pressure monitors, blood glucose monitors and accelerometers; this enabled study participants to use the automated feature on the application to directly upload monitored data from the device monitors. This Healthvault[™] functionality helped to minimize errors with data entry. However, practice site



Figure 6. Primary outcome: AADE 7 self-management behaviors AADE 7, American Association of Diabetes Educators 7

physician co-investigators found it very time consuming to access the Healthvault[™] during clinic visits. Clinical outcomes data at 52 weeks were not consistently available from Clinic D due to technical challenges. e-Healthystrides[®] application has subsequently been successfully migrated to the Health 360x[®] mobile application on Android and iPhones, for current and ongoing studies.

CONCLUSIONS

e-Healthystrides[®] was effective for engaging this motivated cohort of middle-aged African American participants for self-management behavior change. When minority patients with diabetes feel empowered and engaged, they are more likely to adhere to eHealth interventions. This evidence suggests a need for strong relational/social network strategy that incorporates a role for peers and health coaches as apomediaries.

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Conflict of Interest

No conflicts of interest to report.

Author Contributions

Research concept and design: Pemu, Saint Clair, Quarshie, Ofili; Acquisition of data: Pemu, Alema-Mensa, Brown, Saint Clair, Olorundare, McCaslin, Quarshie; Data analysis and interpretation: Pemu, Josiah Willock, Alema-Mensa, Rollins, McCaslin, Henry Akintobi, Quarshie; Manuscript draft: Pemu, Josiah Willock, Rollins, Brown, Saint Clair, Olorundare, Henry Akintobi, Quarshie; Statistical expertise: Josiah Willock, Alema-Mensa, Quarshie, Ofili;

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