International Journal of Public Health (2019) 64:1107–1115
https://doi.org/10.1007/s00038-019-01267-4

ORIGINAL ARTICLE

Development of an urban community-based cohort to promote health disparities research

Susan G. Fisher[1] · Amie Devlin[2]

Received: 6 August 2018 / Revised: 18 March 2019 / Accepted: 30 May 2019 / Published online: 20 June 2019

Abstract

Objectives Many academic medical centers are positioned amidst disadvantaged urban neighborhoods in which healthcare services are underutilized, participation in research studies is low, and need for health improvement is vast. The goal of *Temple Health: Block-by-Block (THB^3)* is to establish a sustainable cohort of Philadelphia residents engaged in individual and community health improvement through health research.

Methods Recruitment of a population-based sample from 11 Philadelphia zip codes began in August 2015. The cornerstone of the project is the in-home, biannual assessment of each subject.

Results The first-year goal of 1000 enrolled subjects was met. Greater than 90% of subjects represent minority racial or ethnic groups; average age is 46 years; 65% of subjects have a high school education or less. A high burden of health conditions exists including obesity (54%), smoking (41%), hypertension (44%), and diabetes (17.8%).

Conclusions THB^3 provides a research infrastructure to promote community participation in a health improvement initiative from which future translational research, health education and preventive services will emanate. The launch of this cohort study has provided extensive lessons regarding urban community-based research and health promotion initiatives.

Keywords Epidemiology · Cohort · Health disparities · Community-based · Urban

Introduction

Medical advances and new technologies have enabled Americans to live longer, healthier lives (The US Burden of Disease Collaboration 2018); however, healthcare quality and access remain suboptimal (Agency for Healthcare Research and Quality 2012). Of particular concern are the persistent, pervasive health disparities related to race, ethnicity and socioeconomic status (Smedley et al. 2003). Since the 1985 Report of the Surgeon General's Task Force on Black and Minority Health (Heckler 1985), there has been a continued escalation of research, knowledge generation and evidence-based interventions to address these challenges. Community engagement strategies have been widely embraced, and many successful community health system partnerships have been established (O'Mara-Eves et al. 2015). Unfortunately, even in the presence of substantial progress, the gaps across race, ethnicity and socioeconomic class remain unacceptably large (Cunningham et al. 2017). Admittedly, these rudimentary categorizations based on the most basic demographic characteristics are inadequate surrogates for the multitude of intricate contextual factors that collectively determine an individual's health status, health beliefs and behaviors, adoption of health interventions, and access to care. These factors arise from not only personal, family, social, religious and cultural underpinnings, but from the structural features of one's environment and community as well. The realities of life in diverse, under-resourced communities are astoundingly complicated, and thereby hinder the adoption of established advances in health promotion and disease prevention.

✉ Susan G. Fisher
Susan.Fisher@temple.edu

Amie Devlin
Amie.Devlin@drexel.edu

[1] Lewis Katz School of Medicine, Temple University, 3440 North Broad Street, Kresge East, Room 211, Philadelphia, PA 19140, USA

[2] Lewis Katz School of Medicine, Temple University, 3440 North Broad Street, Kresge East, Room 245, Philadelphia, PA 19140, USA

Many nationally recognized academic medical centers in the USA are positioned amidst economically distressed urban neighborhoods. Local residents may avoid seeking care at such complex and costly tertiary centers and, not surprisingly, these individuals may be averse to participation in the health-related clinical studies conducted at these institutions. Fueled by a history of mistrust and misunderstanding, community residents often report healthcare system barriers and inequities including decreased access, differential medical treatment and negative encounters including less information, empathy and attention from providers (Scharff et al. 2010). Unfortunately, these perceptions have also hampered widespread dissemination of the remarkable advances in disease prevention and treatment strategies over recent decades. With renewed momentum, many healthcare institutions have recently intensified their efforts and resources to address the challenges of community engagement, working relentlessly toward the goal of establishing themselves as integrated members of their respective communities with a focused commitment toward community health.

Temple University Health System (TUHS) is located in the heart of North Philadelphia. No working American city better epitomizes the epidemic of urban poverty than the patchwork of neighborhoods in North Philadelphia, home to a highly diverse population of ½ million residents of which 50% are African-American (AA) and 26% are Hispanic. With approximately 25% of the residents living below the federal poverty line (US Census Bureau 2017; Public Health Management Corporation 2016), the prevalence of chronic disease is substantially increased, including hypertension (36%), diabetes (15%), mental health conditions (24%), and obesity (37%). Similarly, high age-adjusted mortality rates in this underserved community exemplify an unfortunate but not uncommon scenario—healthcare services are underutilized by local residents, participation of minority individuals in research studies is unacceptably low, and the need for community health improvement is vast (Department of Public Health 2018).

Motivated by the realization that in order to provide cost-efficient, high-quality tertiary care to an underserved population and simultaneously conduct clinical research that addresses the health disparities exemplified within our community, a substantial change in the institutional relationship with the community served by TUHS was imperative. In order to engage our minority community in joint health improvement efforts, Temple University provided support to launch an innovative program to interface directly with the community; it has been branded *Temple Health: Block-by-Block (THB^3)* (Fig. 1).

Fig. 1 Temple Health: Block-by-Block Logo. Philadelphia, PA USA, 2015–2018

The long-term goal of this initiative is to establish a sustainable, multigenerational cohort of diverse neighborhood residents who are philosophically engaged in the concept of individual and community health improvement across the life cycle through health research. Using a longitudinal cohort design, the primary aims are to:

- Enrich minority research participation through clinical research education and access to clinical trials;
- Optimize the institutional research portfolio by providing descriptive health data for developing community-relevant research and augmenting minority participation in these investigations;
- Most importantly, contribute to the health improvement of the community served by TUHS.

Many historic, highly successful cohort studies have been conducted in the USA with the initial intent to either identify etiologic factors associated with incidence of a specific disease entity or to examine the long-term impact of specific risk factors on overall health (Tsao and Vasan 2015; Colditz et al. 2016). THB^3 is somewhat unique from such past cohorts. First, THB^3 is designed to examine the nexus of biologic, social, and environmental determinants of health rather than focusing on an explicit hypothesis regarding a specific exposure, disease or outcome. Secondly, with few exceptions (Taylor et al. 2005), longitudinal studies conducted in the USA have included a very small proportion of minority subjects; given the diversity of the THB^3 target population, enrollment of a sample in which at least 75% of participants self-identified as a minority was anticipated. Lastly, door-to-door recruitment, an approach rarely used in health studies, is being implemented. This report describes the design, data collection methods, first-year enrollment experience and initial sample characteristics of THB^3.

Methods

Pilot study

In Fall 2014, a pilot study was conducted in a Hispanic neighborhood in North Philadelphia, selected to leverage an established partnership between community leaders and institutional faculty interested in community outreach. Community leaders were invited to provide input into the proposed survey instrument, resulting in dilution of desired data due to concerns regarding confidentiality and willingness of residents to provide the desired information. Community residents were hired and trained to enroll and collect data from 50 subjects. While the accrual goal was met, the pilot project demonstrated many challenges related to adequate compliance with structured enrollment procedures, appropriate handling of research data, and allowable access by community leaders to community residents. It was determined that a more gradual approach to community engagement and participation was necessary. Specifically, THB^3 would begin with an institutional-centric approach that engages the community in a consulting role fostered by community feedback, information sharing, and progressive community connections (McCloskey et al. 2011). Survey instruments were revised to provide more comprehensive information, organizational planning and protocols were modified to optimize subject engagement and retention, and funding was obtained to hire a dedicated team of four field specialists, including one long-time resident of North Philadelphia with community outreach and in-home assessment experience.

Recruitment/eligibility

Study recruitment began in August 2015 with a short-term goal of enrolling 1000 subjects in the first year; enrollment is planned to extend for at least 8 years with inclusion of a minimum of 5000 subjects. Eligible subjects must be 18 years of age or older, be able to speak either English or Spanish, have no cognitive disorders that may interfere with the integrity of the informed consent process, and reside in one of the 11 zip codes that are served by Temple University Hospital (Fig. 2: Catchment area for Temple Health: Block-by-Block). With the exception of occasional enrollment at community events, subject recruitment is accomplished via door-to-door canvassing designed to reflect a personal engagement approach to diverse residents across multiple neighborhoods. All eligible members of a household present at the home visit are invited to enroll. Typically, specific clusters of blocks are identified each day for canvassing. While all zip codes are included there has been an initial concentration on the blocks immediately surrounding the hospital which include the greatest density of minority residents. The study has been approved by Temple's Institutional Review Board; consent is obtained from all individual participants included in the study. Each subject is provided a detailed explanation of the study and an information sheet including full contact information for his/her designated Field Specialist and the Principal Investigator. The initial four field specialists were all female with one being African-American and one being Hispanic. Three of the four staff held master's degrees in health-related concentrations; all had previous experience in public health practice roles. The research development contributions of staff with graduate degrees have been key; conversely, the insights regarding local community perceptions and 'real world' impediments to participation provided by staff who have grown up in Philadelphia have been invaluable.

Visit protocol

The cornerstone of the THB^3 initiative is the twice-yearly home visits for collection of descriptive data related to demographic and social characteristics, medical history, biometric measurements including blood pressure, anthropometry and body mass index, health behaviors, and health outcomes from each cohort member. Each visit targets a specific theme as detailed in Table 1.

Survey instruments have been developed using a consensus approach among project faculty, staff and external content experts in order to capture the key constructs of interest within each theme while assuring survey readability and understanding by participants. While some new survey questions have been developed as needed, the intent has been to utilize as many established, validated survey items and scales as possible. Each survey is pre-tested, critically reviewed and revised by the study team to assure simplicity, readability, and ease of administration. Typically, survey administration averages 19 min with a range of 12–30 min. Instructional notes related to clarification of specific question responses, skip patterns, and approved prompts are added to each survey. All data collection tools and study documents have been translated into Spanish by a certified translator. Prior to implementation of each new visit, field specialists are trained in the administration of each survey or biologic measurement procedure with multiple practice iterations to assure accuracy and standardization across staff. To assure quality control, clarifications/revisions and retraining are completed as needed with the staff.

The relatively common practice of offering subjects a financial incentive for participation is not aligned with the THB^3 goal of recruiting individuals 'engaged in the concept of health improvement.' In order to convey the desired bidirectional commitment to this project and avoid

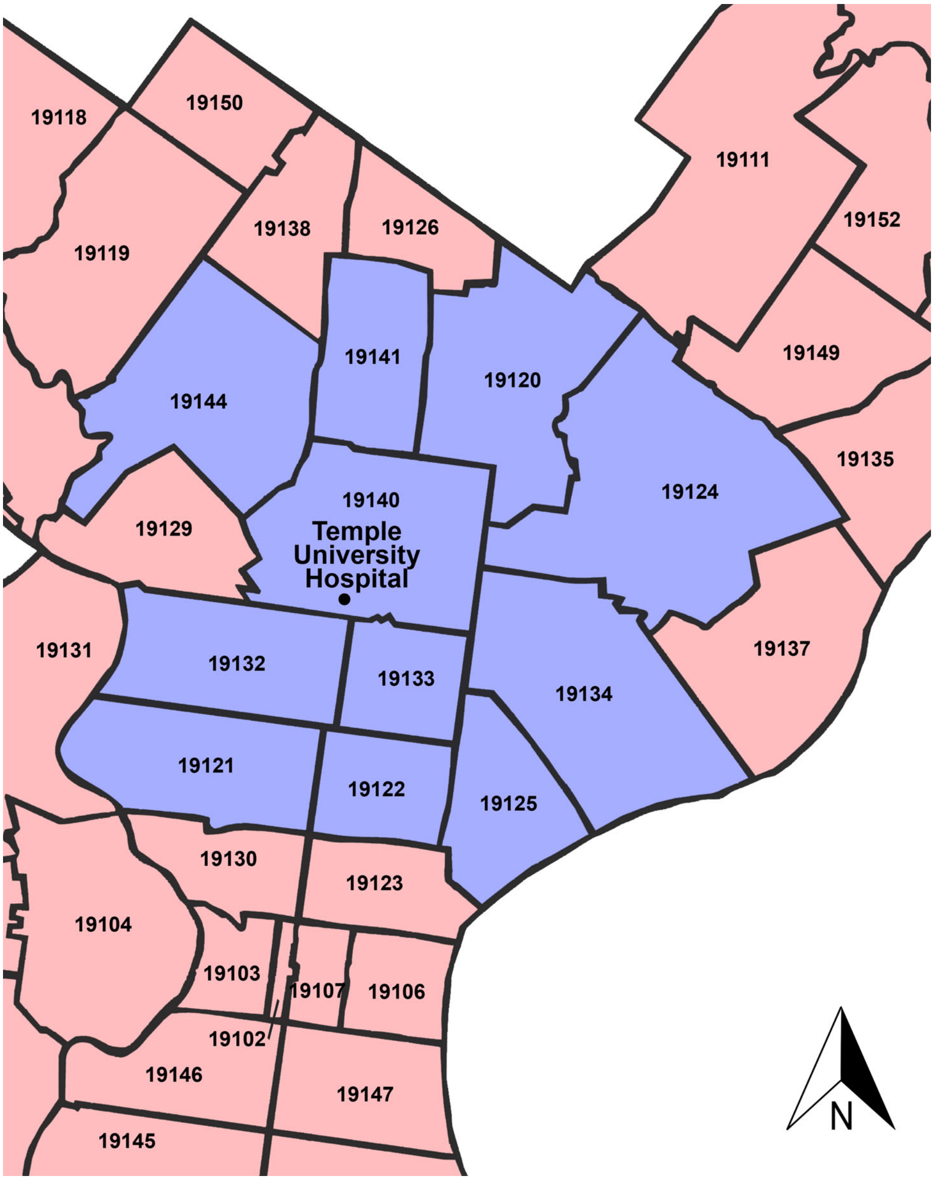

Fig. 2 Catchment area for Temple Health: Block-by-Block. Philadelphia, PA USA, 2015–2018

enrollment of misguided subjects potentially leading to a biased sample, no financial inducements are offered for participation in the core components of THB[3]. The valuable contributions of participants are appreciated and frequently acknowledged via thank you notes and small 'health-related' gifts, i.e., water bottle, flashlight, dental care kit, thermos, umbrella, first aid kit, etc.

Follow-up

Follow-up visits for each subject are conducted by the field specialist who originally enrolled the participant, thereby, promoting an enduring relationship with study staff. These follow-up visits typically occur Monday through Friday during daylight hours. A tracking program using R software (R Core Team 2013) generates a listing of upcoming subject visits that need to be scheduled; the goal is to conduct visits within ± 1 month of the date the visit is due; however, this window is sometimes extended to accommodate participants' availability. Subjects are contacted via phone call, texting, email, or Facebook contact as approved by the subject at the time of enrollment. In the first year, a minimum of three attempts were made to arrange a home visit. If the subject could not be contacted and there was no response from a letter mailed to his/her home address, the subject was classified as 'lost-to-followup.' As detailed later, this policy has been revised.

Table 1 Biannual visit themes and survey topics. Temple Health: Block-by-Block, Philadelphia, PA USA, 2015–2018

Visit theme (follow-up time)	Survey topics
Visit 1 (enrollment) *Demographic and health characteristics*	Contact information, household roster, demographics, employment, insurance, sources of health care, health status and conditions; request to be notified regarding potential participation in other research studies specifically relevant to subject's health
Visit 2 (6 months) *Reported health condition assessment*	Health conditions (onset, type, treatment, status, impact on activities of daily living [ADL])—cancer, diabetes, hypertension, asthma, arthritis, kidney disease, liver disease, lung conditions, mental health, addiction, stroke, obesity
Visit 3 (1 year) *Cancer risk behaviors and screenings*	Anthropometric measures completed, BMI, physical activity, screen time, diet, alcohol, smoking, stress, quality of life, depression, dental hygiene, reproductive history, viral infections, screening practices (breast, PSA, cervical, colon)
Visit 4 (18 months) *Heart health and family history*	Blood pressure measured, cardiovascular (CV) risk perceptions, family history, change in CV risk behaviors; medications, cholesterol control
Visit 5 (2 years) *Neighborhood and environment*	Stress, social/religious support, neighborhood safety, neighborhood satisfaction (transportation, food access, healthcare access) housing conditions (safety, utilities, rodents, guns)
Visit 6 (30 months) *Allergy, asthma and inflammation*	Allergies, allergens, symptoms, treatments, impact on ADLs, detailed atopic dermatitis assessment, vision, hearing

Data management

All surveys, English or Spanish, are verbally administered to subjects; responses are recorded using pencil and paper to maximize eye contact with the subject and minimize electronic distractions, as well as device theft concerns. Upon return to the study office, data are entered into a REDCap database by the field specialist who administered the survey. While visual data checking is conducted by that field specialist, a 10% random sample of all surveys is re-checked by an independent staff member to monitor error rates, identify problematic questions needing clarification/revision by the study team, and make data corrections as necessary.

Participant confidentiality

In addition to routine procedures for data security including limited-access storage of hard copy and electronic data and use of anonymized study participant identifiers, THB^3 subject visits are only conducted by the field specialist team. The THB^3 infrastructure has been made available to other investigators for data acquisition on independent studies; however, data collection for collaborative investigations is conducted only by trained THB^3 field specialists. This decision reflects our goal of respecting the privacy of study subjects, enhancing their trust in the THB^3 team, avoiding an unfortunate perception that multiple 'strangers' are entering their homes, and minimizing possible concerns regarding the sharing of their identity and health information without their approval.

Staff safety

Given that the majority of the THB^3 target population resides in neighborhoods having exceptionally high crime rates including shootings, robberies and drug activity, specific field recruitment procedures have been developed to maximize staff safety. These include: recruitment and THB^3 activities are completed by staff traveling in pairs, specifically the field specialist assigned to that subject and a staff 'buddy'; no canvassing occurs after dark; staff wear branded THB^3 clothing/hats/backpacks to maximize identification; no electronic devices are used in the field, other than THB^3-specific cell phones, to minimize threat of theft; real-time address-specific tracking of staff locations occurs; each specialist carries mace; and staff are trained in CPR, 'street smart' de-escalation/defense techniques, and use of 'warning/exit word' protocols.

Results

The first-year enrollment goal of 1000 adult subjects was achieved. This sample resulted from knocking on approximately 7400 doors, of which 29.4% were answered. The consent rate from answered doors was 36.9%; in 13% of these households, more than one individual was enrolled. Enrollment was supplemented by about 20% sample enrollment at community events. The characteristics of the first 1000 subjects are provided in Table 2; some differences between this initial sample and the target population are notable (Public Health Management Corporation 2016).

Although population-based canvassing efforts resulted in subjects enrolled from all 11 zip codes, early recruitment was concentrated in zip codes in closest proximity to Temple Hospital; these are the neighborhoods with the greatest density of African-American residents and the smallest proportion of Hispanic residents. Among the first 1000 subjects, 74% identified as non-Hispanic, African-American and 16% identified as Hispanic, thereby confirming the willingness of these minority residents (90% of sample) to participate in THB[3] as initially designed. Recruitment restricted to daytime hours is also likely to have yielded some minor sampling bias; subjects were more likely to be female, older and unemployed than the 11-zip code target population. Although slightly better educated than the target population, 65% of the initial cohort has only a high school education or less. Regarding health conditions, the rate of obesity (54% based on standardized measurements obtained by study staff) is much higher than that of the target population (37%) and the self-reported smoking rate (41%) is almost twice that expected (24%). Self-reported prevalence rates of both hypertension

Table 2 Cohort characteristics, (n = 1000). Temple Health: Block-by-Block, Philadelphia, PA USA, 2015–2018

Factor	N^a	Sample percent	Population percent
Gender			
Male	395	39.5	47.0
Female	604	60.4	53.0
Transgender	1	0.1	
Age			
18–44	454	45.4	53.4
45–64	397	39.7	31.5
65 +	144	14.4	15.1
Unknown	5	0.5	
Race			
White	92	9.2	20.8
Black	737	73.7	47.0
Other	150	16.6	32.2
Refused	21	2.1	
Hispanic			
Yes	164	16.4	24.4
No	831	83.1	75.6
Refused	5	0.5	
English speaking	948	94.8	72.0
Education			
Less than high school	218	21.8	26.0
High school	428	42.8	61.0
Some college/graduate school	354	35.4	13.0
Employed	403	40.3	80.0
Home owner	76	38.2	54.0
Health insurance	907	90.7	87.0
Reported conditions/behaviors			
Asthma	267	26.7	23.0
Diabetes	178	17.8	15.0
Hypertension	440	44.0	36.0
Mental health	245	24.5	24.0
Overweight	116	35.9	35.0
Obese	241	54.4	37.0
Smoking	414	41.4	24.0

[a] Counts may not total to 1000 due to missing data

(44%) and diabetes (17.8%) are higher in the initial cohort than the target population (36% and 15%, respectively).

The community response to THB^3 has been very positive. Participants have welcomed staff into their homes and established very amicable relationships with the field specialists. Subjects have been highly engaged, interactive, enthusiastically promote the project to family and friends, and provide constructive feedback regarding THB^3 communications and activities. They have welcomed all health information provided to them and have been exceptionally willing to share personal information with staff including such sensitive topics as HIV status. Many subjects have consented to participate in ancillary research studies that have been offered, some of which have included lengthy interviews related to delicate issues such as mental health and sexual abuse. Gift cards are offered as incentives for ancillary studies that are particularly time-consuming or burdensome.

In this initial group of 1000 subjects, 80% and 67% have been retained in the study for 6 months and 1 year, respectively, based on the original procedures for follow-up. Efforts to maintain subject engagement have included: a quarterly newsletter that includes project updates and highlights of special interest/stories/talents of some of our subjects; Thanksgiving raffles of several turkey dinner gift baskets; health-related games with prizes for participant winners; participation thank you cards; follow-up visit text messages; and a study Facebook page. At the completion of the enrollment visit, each participant is asked for approval to be approached about other relevant clinical studies. About 95% of participants agree to consider participation in other studies and to be recontacted about such studies. Consent and enrollment into other studies may be completed at an extra visit independent of the biannual THB^3 visit or may occur during a scheduled THB^3 visit depending on the required time commitments.

Discussion

For many decades, cohort studies have contributed significantly to the identification of risk factors associated with some of our most burdensome diseases, thereby providing important strategies to address disease prevention and health improvement. As a population-based cohort study, the minority-rich THB^3 sample drawn from a diverse, urban population of ½ million individuals will be extremely valuable in addressing hypotheses related to the vast health disparities that remain relentless in national morbidity and mortality outcomes. The recruitment of 1000 subjects within the first year of the study demonstrates the success of the research approach and the willing partnership of community members in this initiative. Given that community residents have no pre-notification of our home visit or invitation to participate in research and no incentives are offered, our rate of participation based on doors answered (37%) compares well to other published participation rates (Galea and Tracy 2007; Flynn et al. 2013; Hillier et al. 2014). We anticipate that as community awareness of THB^3 increases, participation rates will also continue to rise.

Based on the expanding number of follow-up visits, a future recruitment goal of 500 new enrollees each year has been set. The field specialist staff has gradually increased to nine individuals of which one was a first-year THB^3 participant, thereby providing additional community/participant perspectives related to study implementation and future planning. The personalized interaction between THB^3 staff and community residents driven by the values of respect and cultural sensitivity has been paramount to our recruitment success. It is anticipated that this cohort will be representative of the needs and health characteristics of many urban communities across the USA; at the least, the scientific findings emanating from this cohort will provide direction for new hypotheses as well as confirmatory studies in other minority populations.

As the cohort matures, a few challenges are apparent. Most importantly, retention must be at the forefront of our priorities. Given the challenging socioeconomic characteristics of the THB^3 population, it is highly unlikely that our retention rates will ever approach the exceptionally high rates of such seminal studies as the Framingham Health Study (99%) (Tsao and Vasan 2015) and the Nurses' Health Study (94%) (McCloskey et al. 2011). Early retention of the initial 1000 subjects in THB^3 has, however, been much lower than expected or desirable. The primary reason for subject losses has been inability to contact the participant with three successive phone or messaging attempts. In this community-based population, interruption or extended loss of cell phone service is common due to financial constraints and simply lack of attention to dwindling phone call minutes available. Cell service transitions are delayed and often result in a new phone and a new number, thus hindering staff efforts to contact participants. In hindsight, the initial decision to classify a subject as 'lost' based on three failed attempts to reach that subject via the contact phone number was too stringent. A review of the enrollment procedures identified several other factors contributing to subject attrition including: inadequate staff consideration at the time of enrollment to subtle indications regarding lack of subjects' commitment to or understanding of the longitudinal nature of the study design; staff tendency to cease subject contact following an unsuccessful participant interaction, i.e., subject declined to commit to a visit at that time or subject was not available at the time of a scheduled visit, in order to avoid being perceived as an annoyance; and decreased use of alternative methods to contact subjects when phone service had been disconnected. In order to address this retention problem, significant and effective changes were made after this initial recruitment wave. A 'gamechanger' has been the institution of 'drop-by visits.' Field specialists now drop-by the homes of subjects who are due for follow-up visits when they are in the neighborhood or on specific days set aside solely for spontaneous home visits of difficult to reach subjects. Interestingly, in these situations, if the participant happens to be home he/she is often quite willing to complete the visit survey at that time. If at the time of a drop-by or a scheduled visit there is no answer at the door, a door hanger is left requesting that the subject contact his/her THB^3 field specialist. Additional strategies instituted are: increased attempts to contact subjects by phone with more variety in time of day calling; Facebook messaging after participant approval at enrollment has been an extremely effective tool for reaching subjects; and increased contacts with relatives who are able to assist with subject connections. While the importance of retention in cohort studies has been well documented, the early THB^3 experience clearly illustrates the impact of complex social and economic challenges in a resource-poor community on individuals' abilities to maintain adequate consistency in daily activities in order to enable them to meet exceptional obligations such as research participation. By carefully examining these deficiencies, identifying new approaches, and educating staff on retention as a key priority, retention among subjects enrolled in year 2 has increased to 91% at 6 months and 79% at 1 year. Data also indicate that the likelihood of attrition decreases over follow-up time; as a subject's investment in the study increases, it seems so does his/her commitment to THB^3.

The second challenge that must be addressed in THB^3 is educational in nature. While it is clearly recognized that both observational and active integration roles for students in this community-based, door-to-door data collection effort would provide a unique learning laboratory, such educational opportunities have yet to be offered. The ethical and practical tension between assuring confidentiality, respect and personal engagement for study participants while concurrently training, supervising, and scheduling students with different levels of community-based outreach preparedness is problematic. The goal of providing educational opportunities for trainees will continue to be sought.

Lastly, one major goal of THB^3 was to leverage the infrastructure that has been established to provide descriptive data for grant applications, provide an identified pool of willing subjects to participate in future studies, and attract funding from other investigators to sustain the basic program. Four externally funded, ancillary studies have been initiated within the THB^3 framework. It is critical that additional independent studies access the successful THB^3 structure in order to accelerate minority research participation and leverage the established infrastructure.

THB^3 provides an epidemiologic research approach to create a new level of community involvement and health improvement. This diverse cohort is poised to serve as a rich resource of primary data from which a broad scope of multi-level risk factors may be delineated. THB^3 gives a voice to the community regarding their health priorities, and it promotes research agendas responsive to these identified concerns within the health system through dissemination of priorities to investigators and by targeted invitations to colleagues to contribute to the development of collaborative research opportunities. As the cohort matures, longitudinal data collection will enable new research hypotheses to be addressed in a timely, cost-efficient manner, thereby enhancing access of this minority population to the most innovative/promising therapies and supporting their participation in clinical trials. This bidirectional paradigm of enhanced clinical research through community action is translatable to many US academic health centers positioned amidst diverse, urban neighborhoods.

Conclusion

Door-to-door enrollment into a community-based cohort study provides an extraordinary opportunity to establish relationships with a diverse, minority population in an urban setting and to enroll and educate community residents about the conduct and benefits of health-related research. Data collection in residential homes affords an invaluable window of awareness into the vast matrix of unique social, behavioral and environmental factors that may contribute to health disparities. These insights are crucial for the development of future biomedical research leading to successful health promotion, disease prevention, and effective treatment strategies. While basic science and clinical research remain as important enterprises to meet the challenges of health improvement in the twenty-first century, THB^3 serves as a springboard to optimize community participation in these efforts and assure that future scientific discoveries result in better health for all Americans.

Acknowledgements Funding was provided by Temple University (Grant: Strategic Initiative).

Authors contributions SGF conceived of this study, acquired the financial support and grant funding to support the effort, and directed the development of all data collection tools and study methods. She has written the manuscript and fully approves of the final submitted version. AD developed the implementation tools for subject recruitment, selected and implemented software and databases to coordinate study activities and store data, contributed significantly to survey instrument development, and supervised the field team conducting the data collection. The second author has reviewed and suggested revisions as appropriate to the manuscript, and she has provided approval of the final submitted version.

Compliance with ethical standards

Conflict of interest None of the authors have any conflict of interest to disclose.

Research involving human subjects All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards.

Informed consent As per Institutional Review Board standards, informed consent was obtained from each individual participating in this study. This has also been specified in the manuscript text.

References

Agency for Healthcare Research and Quality (2012) National Healthcare Disparities Report 2011 (AHRQ Publication No. 12-0006). Department of Health and Human Services, Rockville, MD

Colditz GA, Philpott SE, Hankinson SE (2016) The impact of the Nurses' Health Study on population health: prevention, translation and control. AJPH 106(9):1540–1545

Cunningham TJ, Croft JB, Liu Y, Lu H, Eke PI, Giles WH (2017) Vital signs: racial disparities in age-specific mortality among blacks or African-Americans—United States, 1999–2015. Morb Mortal Wkl 66(17):444–452

Department of Public Health (2018) Health of the City. City of Philadelphia

Flynn A, Tremblay P, Rehm J, Wells S (2013) A modified random walk door-to-door recruitment strategy for collecting social and biological data relating to mental health, substance use, addiction and violence problems in a Canadian community. Int J Alcohol Drug Res 2(2):7–16

Galea S, Tracy M (2007) Participation rates in epidemiologic studies. Ann Epidemiol 17:643–653

Heckler MM (1985) U.S. Department of Health and Human Services, Report of the Secretary's Task Force Report on Black and Minority Health Volume I: executive summary. Government Printing Office, Washington

Hillier A, Cannuscio CC, Griffin L, Thomas N, Glanz K (2014) The value of conducting door-to-door surveys. Int J Soc Res Methodol 17(3):285–302

McCloskey DJ, McDonald MA, Cook J, Heurtin-Roberts S, Updegrove S, Samplson D, Gutter S, Eder M (2011) Community engagement: definitions and organizing concepts from the literature. In: Principles of community engagement, 2nd edn. Center for Disease Control and Prevention. NIH Publication No. 11-7782

O'Mara-Eves A, Brunton G, Oliver S, Kavanagh J, Jamal F, Thomas J (2015) The effectiveness of community engagement in public health interventions for disadvantaged groups: a meta analysis. BMC Public Health 15:129. https://doi.org/10.1186/s12889-015-1352-y

Public Health Management Corporation (2016) Temple University Health System Community Health Needs Assessment, Philadelphia, PA

R Core Team (2013) R: a language and environment for statistical computing. R Foundation for Statistical Computing, Vienna, Austria. http://www.R-project.org/

Scharff DP, Mathews KJ, Jackson P, Hoffsuemmer J, Martin E, Edwards D (2010) More than Tuskegee: understanding mistrust about research participation. J Health Care Poor Underserved 21(3):879–897. https://doi.org/10.1353/hpu.0.0323

Smedley BD, Stith AY, Nelson AR (eds) (2003) Unequal treatment: confronting racial and ethnic disparities in health care. National Academies Press, Washington

Taylor HA, Wilson JG, Jones DW, Sarpong DF, Srinivasan A, Garrison RJ, Nelson C, Wyatt SB (2005) Toward resolution of cardiovascular health disparities in African Americans: design and methods of the Jackson Heart Study. Ethn Dis 15(4 Suppl 6):S6-4-17

The US Burden of Disease Collaborators (2018) The state of US health, 1990–2016 Burden of diseases, injuries and risk factors among US states. JAMA 319(14):1444–1472

Tsao CW, Vasan RS (2015) Cohort Profile: the Framingham Heart Study (FHS): overview of milestones in cardiovascular epidemiology. Int J Epidemiol 44(6):1800–1818

U.S. Census Bureau, Partnership and Data Services Branch (2017) American Community Survey. Washington, DC