The Impact of Community Engagement in the Design and Implementation of the Flint Registry

Nicole Jones, PhD,[1,2] Kenyetta Dotson, MSW,[1] Kirk D. Smith, MHSA,[3] Lawrence Reynolds, MD,[2] Kent Key, PhD,[4] Mona Hanna-Attisha, MD, MPH[1,2]

[1] Michigan State University–Hurley Children's Hospital Pediatric Public Health Initiative, Charles Stewart Mott Department of Public Health, Michigan State University College of Human Medicine, Flint, MI, USA
[2] Department of Pediatrics and Human Development, Michigan State University College of Human Medicine, Flint, MI, USA
[3] Greater Flint Health Coalition, Flint, MI, USA
[4] Charles Stewart Mott Department of Public Health, Michigan State University College of Human Medicine, Flint, MI, USA

Corresponding author: Nicole Jones, Pediatric Public Health Initiative, Michigan State University College of Human Medicine, 200 E 1st St, Flint, MI 48502, USA; warnerni@msu.edu

Note: The majority of this work was completed while Kirk D. Smith was affiliated with Greater Flint Health Coalition. His current affiliation is Hamilton Community Health Network, Flint, MI, USA.

ABSTRACT

Background: The Flint water crisis (FWC) was a public health tragedy caused by crumbling infrastructure, subverted democracy, and indifference toward a predominantly poor and Black community that resulted in lead-in-water exposure, Legionnaires' disease, and emotional and health-related trauma. Through the cooperation of community partners, the Flint Registry (FR) was conceived to track long-term health and improve public health via service connections.

Objectives: This study sought to share the FR's community-partnered, multi-tiered engagement strategy and determine the efficacy of this strategy to engage the community and reach Flint residents.

Methods: Community engagement and impact were measured by collecting and describing feedback from the community engagement strategies and by comparing the demographics of the enrollees recruited through community-engaged recruitment (CER) and non-CER methods. Enrollees indicated how they heard about the FR; CER involved direct interaction with a community member.

Results: Community engagement strategies incorporated ~1200 people and 7 funded organizations, impacting 22 key areas of FR design and implementation. Over 50% of enrollees heard about the FR through CER methods. They were, on average, more likely to be younger, female, Black/African American, and living outside of Flint during the FWC.

Conclusions: Community engagement elevated voices of those impacted by the FWC. CER methods were as effective as non-CER methods. Although there were no differences in screened measures of social vulnerability, there were in age, gender, and race. CER methods may increase

participation and build trust in populations which historically are hesitant to participate in public health efforts.

KEYWORDS: Community engagement, Flint water crisis, Public Health, Public health registry, Community partnerships, Health promotion, Midwestern United States, Urban Populations, Academic-government-community partnership, Equity

INTRODUCTION

In April 2014, in a breakdown of democracy and driven by austerity, the drinking water source of Flint, Michigan, was changed from the Great Lakes to the Flint River. The water, lacking proper treatment, wreaked havoc and exposed governmental indifference toward a predominantly poor and Black community. The Flint water crisis (FWC) resulted in a myriad of short- and long-term consequences including lead-in-water exposure, Legionnaires' disease, health and development concerns, and overwhelming trauma from governmental betrayal and broken trust.

The public health response supporting long-term recovery has been driven by the principles of health equity, restorative and environmental justice, participatory democracy, and self-determination.[1-5] Embracing these concepts is fundamental to successful work in any impacted community; however, community-partnered work is especially critical in Flint for several reasons. First, the FWC was an environmental injustice rooted in the dismissal of a predominantly poor and Black population. Flint residents were vocal and organized, raising concerns about the water, yet their voices were not valued. Second, the water change transpired under usurped democracy. Flint was governed by state-appointed unelected Financial Emergency Managers who were unaccountable to residents' concerns. Lastly, the FWC severed the trust between institutions charged with protecting a population and those dependent on their responsibility. A central tenet of environmental and health justice, as well as fundamental to democracy and the rebuilding of trust, is meaningful participation in decision making. Thus, a response that is driven, informed, and partnered by community is essential to Flint's recovery – and applicable to public health efforts in similarly-disenfranchised communities. Espousing these

principles, the FR was designed, built, and implemented to include and elevate community voices.

FR Background

The idea of the FR was conceived by members of the local health community and recommended to the Emergency Operating Center during the federal declaration of emergency. Simultaneously, Flint residents suggested creating a database for long-term tracking of health at community townhalls. Likewise, the governor-appointed Flint Water Advisory Task Force, which included a Flint resident and physician (co-author LR), recommended creating a "toxic exposure registry."[4]

In 2017, Flint-based Michigan State University (MSU)–Hurley Children's Hospital Pediatric Public Health Initiative (PPHI) received a planning grant from the Michigan Department of Health and Human Services to prepare to create a lead exposure registry. In late 2016, Congress funded a grant to Centers for Disease Control and Prevention (CDC) for the creation of a Flint Lead Exposure Registry. Collaborating with the City of Flint and Greater Flint Health Coalition, MSU applied for and received the CDC grant, which began August 2017.

Designed as a public health intervention in response to the FWC,[6] the FR was designated by the CDC as a Public Health Authority. Similar to other large-scale responses to environmental exposures such as the World Trade Center disaster and a polybrominated biphenyls food supply contamination event, the FR is built to conduct longitudinal surveillance.[7,8] Also similar to other responses to public health crises, the FR utilized a community-informed response.[9] However, the FR is unique in the goal of creating a registry to improve public health via an expansive referral

network. Key FR outcomes, defined by the CDC, include increased use of preventive services, reduced environmental lead exposures, lower blood lead levels, better health, and fewer developmental delays among participants.

Recognizing the federally directed outcomes and the responsibility to be community partnered, a community engagement strategy was developed to design and implement the FR. This paper shares the FR's community-partnered engagement strategy, including the methods for inclusion of different strategies, the impact of community engagement, and challenges and successes of our approach.

METHODS

Project Strategy Development

A strategy was established to deliberately and formally maximize community engagement in the FR's design and implementation. Partnerships were sought to further elevate residents' voices, restore community trust, and build multi-sector relationships within our collaborative structure. Community was defined as residents impacted by the FWC and Flint-based organizations that could support outreach and recovery activities. To be inclusive, organizational partners and community leaders that had strong relationships within Flint were strategically identified based on key sectors of the community (Table 1). Strategies to include resident voices involved both broad activities (e.g., soliciting feedback via survey) and targeted activities (e.g., conducting a focus group with Hispanic residents, forming a parent partners group). The strategy for community engagement evolved throughout the design and implementation period, with additional partners joining. The final engagement strategy included partnering with community-

based Greater Flint Health Coalition (GFHC), conducting co-outreach with local organizations, leveraging a parent partners group, establishing a community advisory board, hosting community events, collecting pre-enrollment feedback, integrating a youth advisory council, conducting focus groups, developing a community ambassador program, hiring and training community members, structuring a community referral network, adding the Director of Community Engagement and Implementation position and receiving local community ethics review board approval. We present the timeline of implementing the community strategy (Figure 1) and a brief overview of each activity below.
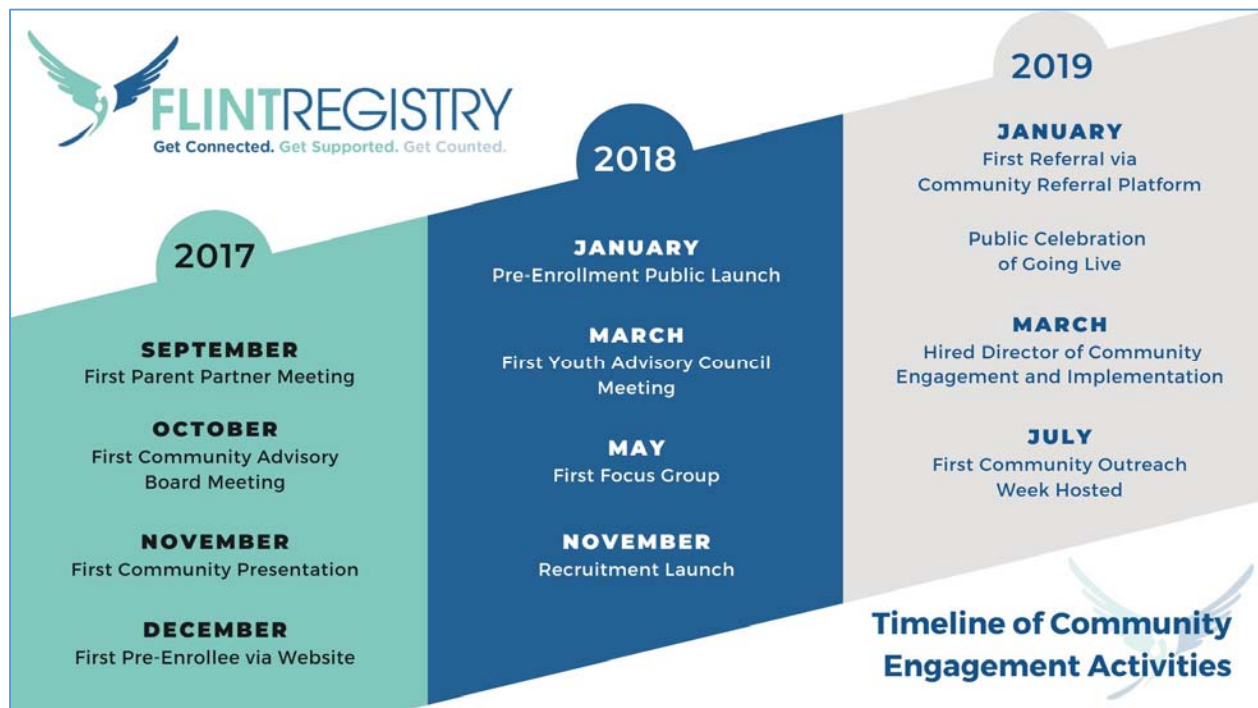

Figure 1. Timeline of Flint Registry Community Engagement Activities

Community Engagement Strategies

Registry Leadership

An academic-government-community partnership, the FR's leadership team comprised representatives from MSU-PPHI, the City of Flint, and the GFHC. The leadership team was actively involved in the FR's conceptualization, design, and implementation since 2015. The community partner, GFHC, is a local decades-old non-profit striving to improve Flint and Genesee County residents' health status and the quality and cost effectiveness of the community's health care system.

Co-outreach

The GFHC directed outreach activities by leveraging existing community partnerships and utilizing a co-outreach strategy which included funding local agencies. Co-outreach allowed organizations to share information about the FR while promoting or implementing their own programs. Funded co-outreach partners included the City of Flint, Genesee Intermediate School District, the Crim Fitness Foundation, Genesee Health Plan, Genesee County Medical Society, Genesee Health System, and GFHC. Funded partners met monthly to provide input and feedback on outreach, as well as implementation.

MSU-PPHI Parent Partners

Fourteen months before launching the Registry, the MSU-PPHI, along with the GFHC, formed a parents' group to create active parent partners to inform the work of local programs to improve the health of children in Flint. A local team member who was coordinating parent advisory boards for other cross-sector groups identified parents who were engaged in FWC recovery efforts via participation in community townhalls and on other parent boards. Demographically diverse parents were selected to include members from all City of Flint wards as well as parents

who left post-FWC but remained in the area. Parent partners included parents, grandparents, and non-biological caregivers. Parents from existing area parent advisory groups were invited to join to establish linkages across a network of groups.

FR Community Advisory Board

Thirteen months before enrollment began, the FR Community Advisory Board (CAB) was developed to promote communication between residents, parents, public agencies, schools, and other organizations to facilitate input, increase community awareness, and coordinate activities to benefit those the FR serves. Key sectors of the Flint community were identified: faith, workforce development, seniors, education, academia, organized labor, non-profit, government, philanthropy, media, health care, behavioral health, parents, youth, and law enforcement. Community leaders in the key sectors who lived, worked, or served in the Flint community were selected, with a preference for Flint residents.

Community Presentations

Community presentations about the FR began twelve months before enrollment. Presentations were given to local organizations to share information about the upcoming project and gather community input.

Pre-enrollment Feedback (December 2017)

At the CAB and Parent Partners' request, a website was launched to enable people to express interest in the FR before official enrollment. During the "pre-enrollment" process individuals shared contact information and provided comments on the proposed FR project.

MSU-PPHI Flint Youth Justice League

Eight months before enrollment launched, Flint-area youth were brought together to create the MSU-PPHI Flint Youth Justice League. Members provided guidance, suggestions, and recommendations for the FR from a youth perspective.

FR Focus Groups

To gather input from additional community members and allow those who were less engaged and less connected to local organizations to shape the FR, two series of focus groups targeted at specific demographic populations were conducted with GFHC staff (MSU health risk communication experts provided training and oversight). Approximately six months before the FR launch (5/9/2018 – 6/12/2018), nine focus groups (68 participants) were conducted with specific audiences, including seniors, teens, adults who are deaf and use American Sign Language (ASL), the Hispanic community, and more generalized residential groups from different areas of Flint. Focus groups (~90 minutes) were held at community sites across Flint. Input solicited from the first series focused on creating an awareness of the FR, recommendations for services, perceived barriers to participation, incentive suggestions, communication strategies, and the enrollment process.

Approximately six months after launch (6/13/2019 – 8/6/2019), seven focus groups (62 participants) were conducted. Topics focused on marketing and outreach strategies with emphasis on evaluating awareness and perceptions of the FR, describing opportunities for

outreach and marketing, evaluating existing marketing strategies, and describing ways to improve trust in the FR.

FR Ambassador Training

Coordinated by the GFHC Director of Outreach, the FR Ambassador training program was established to build a network of FR community champions. All FR Ambassadors complete a training workshop that provides an overview of the project, answers to frequently asked questions (FAQs), and a checklist on how to use their training in the community.

FR Team Members

Being physically based in Flint and providing a local engine for employment and professional development was central to the FR's design. The FR is located downtown, in the MSU Flint building, approximately 50 miles from MSU's main campus. Rather than utilize a survey call center on central campus or elsewhere, the project hired and trained a local Flint-based survey interview team.

Director of Community Engagement and Implementation

A Director of Community Engagement and Implementation was hired to ensure an equitable and representative leadership voice in the direction and programming of MSU-PPHI. The Director (co-author KD) was a Flint resident with a history of connecting resources and services to residents, working with grassroots organizations and faith communities across Flint, and had worked in the non-profit and governmental sector for over twenty years. The background,

interaction, and feedback from the Director of Community Engagement and Implementation enabled the FR to strengthen existing partnerships and develop new partnerships.

Community Ethics Review Board Approval

The MSU Human Subjects Protection Program, responsible for reviewing the FR IRB application, determined the project was a non-research public health registry. Additionally, this project was reviewed and endorsed by the local Community-Based Organization Partners – Community Ethics Review Board, which offers an ethical review process that promotes an understanding of ethical research conduct and demands accountability in Flint and Genesee County.[3]

FR Design

The FR eligibility criteria, key goals, and evaluation criteria are defined in the CDC notice of funding opportunity. Individuals were eligible to participate if they lived, worked, or went to school or daycare at an address serviced by the Flint water system from April 25, 2014 to October 15, 2015 (dates on Flint water system) or were born before August 1, 2016 and exposed prenatally. A survey was developed that elicited service eligibility, service utilization, lead exposure, child development, physical health, and mental health. Survey responses connected individuals to nutrition, health care, lead elimination, and child development resources. Race was self-reported to determine the representativeness of FR participants as compared to the total eligible denominator, allowing the FR to prioritize potentially underrepresented demographics for outreach and enrollment. Race was also collected, along with other social determinants of health, to identify and address potential disparities. Race categories were based on the US census

(American Indian or Alaska Native; Asian; Black or African American; Native Hawaiian or Other Pacific Islander; White or Caucasian; and Other); however, based on community feedback, Middle Eastern or North African was added. Recruitment is ongoing with over 18,000 individuals enrolled and over 24,000 referrals to services made through December 2021.

Measuring Community Engagement and Impact

We measured the impact of community engagement in two ways. First, by qualitatively describing the feedback from the above community engagement strategies and how that feedback impacted the FR in key areas. Second, by quantitatively comparing the volume and demographics of enrollees recruited through community-engaged recruitment (CER) versus non-CER methods. In the quantitative analysis, results are reported separately for the two largest race groups: Black or African American only and White or Caucasian only. Due to small sample sizes, all other races and individuals who reported multiple races are summarized in a single group labeled "other." Enrollees were asked to indicate how they heard about the FR; multiple options could be selected. Responses were classified as CER if they involved a direct interaction with a community member or non-CER (Table 2).

RESULTS

Our community engagement strategies formally incorporated almost 1,200 people and seven funded organizations. Table 3 defines key areas of potential impact (N=22) and Table 4 summarizes the impact of each community engagement strategy.

Qualitative Results of Community Engagement Process on Key Areas of Impact

Impacts on Marketing and Outreach

The marketing and outreach strategy and materials were created and continuously adapted in response to community requests. The project name, logo and tagline were designed by community members. The Parent Partners suggested the mythical Sankofa bird as a logo (Figure 2). The Sankofa bird symbolizes moving forward, while acknowledging the past, and prioritizing the young. Community members also suggested the tagline "Get Connected. Get Supported. Get Counted." to better explain the overall mission of the project rather than solely using the word "registry." The CAB further expanded on the tagline, suggesting that "Get Connected" means the FR is positively connecting the community. "Get Supported" means the FR is referring to services to support people and "Get Counted" means the FR is a place to tell your story of how the FWC impacted you. These ideas became the basis for the marketing campaign used to promote the FR.

Figure 2. Flint Registry Logo and Tagline Designed by Parent Partners and Community

Advisory Board

The community requested specific marketing products such as infographics, videos, social media posts, and community member testimonials. CAB members also suggested the development of messaging that articulated the long-term benefits of participation for individuals, families, the Flint community, and for other communities struggling with similar issues.

CAB members pointed out community needs and how the FR could address them as part of the marketing and outreach strategy. For example, the FR provided paper fans for churches, hosted food giveaways during the pandemic, and coordinated mental health resource fairs. Board members also discussed ways to address the lack of trust in the community, such as utilizing best practices and techniques of successful registries around the country, maintaining an updated website, and creating a public dashboard.

CAB members contributed to the overall outreach strategy in multiple ways and served as community connectors for the FR. They provided guidance on how to reach out to certain populations (e.g., ASL/Deaf community, faith community, LatinX community), suitable locations for community events, where to advertise, and specific organizations that should be included as part of the outreach strategy. Our Director of Community Engagement and Implementation worked with the GFHC's FR Outreach Director to engage and connect residents to the FR. The directors provided FR staff with guidance on effective participant engagement strategies, as well as trauma-informed practice, and helped design the FR survey and marketing materials. CAB and Flint Youth Justice League members also directly participated in outreach and marketing by providing video testimonials, handing out FR materials, and speaking at press events.

Community members requested that marketing and outreach materials include both English and Spanish versions and that videos include captioning to accommodate the ASL/Deaf community. Pre-enrollment feedback also included suggestions of specific locations or populations to target outreach and marketing. Recommendations were considered and incorporated into strategies,

including providing reoccurring opportunities in high-density locations. Funded co-outreach partners implemented a coordinated outreach strategy to engage geographic and demographic community sectors.

Impacts on Data Collection Methods and Referrals

Community input was part of choosing the informatics solution, addressing data security/privacy concerns, selecting survey content, designing the method of delivering surveys, and creating the service referral strategy. Prior to finalizing the informatics plan for collecting data, the Parent Partners reviewed the strategy, which required online surveys to be collected through an email account or via the partnering medical center's Epic software.[10] The Parent Partners requested that the FR find alternate solutions that did not require an email address nor include any perceived connection with medical records. Consequently, a process for completing online surveys which did not require an email nor medical record account was designed.

Feedback from community presentations was collated into a list of FAQs which was shared on the FR website. Throughout the FR implementation, the FAQs continued to populate answers based on community feedback and partner input. Data security/confidentiality was a common community concern that was addressed by the FAQs. The FR also built a consent process which included information about how data would be kept secure and confidential. Examples of how data were kept confidential included implementing data security measures, restricting access based on staff roles, providing training to staff on security and confidentiality, and utilizing study IDs and de-identified datasets.

Members of the CAB and Parent Partners piloted surveys, and content was adjusted based on feedback. For example, questions about adverse childhood experiences (ACEs) were removed from the survey because community members found them too invasive. Questions about discrimination were added at the CAB's request. Other additions included a qualitative question about the way the FWC may have impacted eating habits and questions about pregnancy complications. Community members' pre-enrollment comments about mental health, rashes, and pet health were also incorporated into the survey.

Community members looked for ways to reduce barriers to survey completion, such as having the survey be available online, through mail, over the phone, and in person. This feedback came from multiple sources, including pre-enrollment comments which mentioned concerns about lack of internet access or transportation. Community asked that surveys be available in Spanish and that support be provided for the ASL/Deaf community. The FR implemented a multi-modal survey, hired a Spanish-speaking team member, and provided an ASL signer if needed for surveys completed in person. Community partners were part of developing the referral process, suggesting agencies/services to which enrollees should receive referrals and providing regular updates on changes in service availability. Pre-enrollees also mentioned specific organizations for partnerships and referral. They frequently asked about the City of Flint pipe replacement program, which was incorporated into the FR referral process and became the top referral for adult enrollees.

Impacts on Outcome Reporting

Community partners provided feedback on what results should be shared and how to share them. Community input was received on the format of the FR website and public reports. Community members asked for images and graphics that were easily readable. Parent Partners provided feedback on a proposed letter to parents that would share the results of standardized child behavioral-screening instruments from the survey. Based on their feedback, the results were not shared with parents as they found the idea of screening results unhelpful because parents would prefer a clinical diagnosis.

Quantitative Impact of Community Engagement on Enrollment

More than half of enrollees who completed their baseline survey reported that they heard about the FR through at least one CER method. On average, CER participants were younger and more likely to be female, Black or African American, and living outside of Flint during the FWC (Table 5).

DISCUSSION

Cognizant of historic and systemic inequities that stifle inclusion, compounded with the acute injustice of the FWC, community participation was a foundational priority in the FR's design and implementation. At project initiation, community concerns focused on building trust and creating strong data security and confidentiality policies. As the project evolved, most feedback centered around outreach and marketing ideas and implementation. Finally, as data collection progressed, community members shifted to defining ideas for sharing outcomes. Regardless of

the FR phase, community feedback emphasized accessibility, inclusion, and lowering participation barriers.

As a public health registry designed to mitigate the impact of the FWC, it was important to connect with as many people as possible. Our CER strategies increased enrollment considering over 50% of individuals who joined had heard about the registry through at least one CER method. Our CER strategies were as effective at reaching individuals who would benefit from the FR as our non-CER methods. Measures of social vulnerability were similar between the CER and non-CER groups. However, there were differences in age, gender, and race. Overall, females were more likely to participate in the FR and to report hearing about the FR through a CER method. This was likely due to partnership with local community health workers in Flint Community Schools who recruited school-age children and their primary caregivers (predominantly mothers). Although non-CER was also directed at school-age children and caregivers, CER may have been more effective in this population. Of note, Black or African American enrollees were also more likely to report hearing about the FR through a CER method. This finding suggests that CER strategies may be successful in breaking down barriers to participation and building trust in survey research for populations historically less likely to participate. Previous research demonstrates lower overall enrollment rates for Black participants in medical and survey research[11-14] and suggests that community engagement methods may increase enrollment in clinical trials.[15]

Our community engagement strategy created a more inclusive process. In addition to including two community organizations in our leadership structure, we included feedback from over 1000

individuals or organizations. By deliberately including and engaging different sectors of the community and using different methods we got a wide variety of input. This feedback allowed us to implement continuous quality improvement as community members regularly evaluated our progress and provided input on concerns they heard from others. The increase in enrollment due to CER increased the potential number of people connected to services to support overall health and recovery.

Many suggestions provided by community mirrored best practices in the academic survey methods literature such as using multiple recruitment strategies and training staff on effective and trauma-informed communication.[16,17] Additionally, board members recommended adopting techniques from established registries to build trust. Some of these methods we implemented included utilizing validated and standardized survey tools when possible, launching a pre-enrollment phase for early sign-ups, and utilizing databases from other organizations as a recruitment tool.[18] A unique aspect to the FR is that we left enrollment open for an undetermined amount of time to continue to provide service.

A benefit beyond feedback on the FR project was the partnership that developed between the community and FR leadership. There were several times community members asked the FR to play a leadership role in the public health community such as communicating to the City of Flint the need for assistance with water bill payments, spreading the word about the importance of wearing masks during the pandemic, and encouraging service providers to increase accessibility of services. A great advantage was the FR's ability to lean into the community engagement approach by serving as and working collaboratively with trusted partners in the community to

rebuild community trust. As a result, the FR successfully elevated the voice of those impacted by the FWC.

Our community engagement approach had some challenges. It required a significant time investment throughout the entire project. Almost 12 months were spent gathering and implementing feedback prior to project launch. We also faced barriers in implementing some feedback such as funding restrictions, insufficient staff capacity/time, participant privacy, and suggestions that were out of project scope and/or contradictory. These barriers created frustration for community who were invested in the project and wanted to see their suggestions implemented.

From global public health crises like a pandemic to local interventions, our community engagement approach is applicable. Over 5000 enrolled in the registry in response to CER, and the CER and non-CER samples were comparable on health risk factors. As a result of FR implementation, over 24,000 referrals were made to services for enrollees. Community engagement methods can assist with recruiting and delivering public health services to a larger number of people, especially those historically disenfranchised. With regard to public health efforts, our findings suggest that community engagement methods can increase response rates and engage populations with high levels of mistrust.

REFERENCES

1. Lewis EY, Sadler RC. Community-academic partnerships helped Flint through its water crisis. Nature. 2021 Jun;594(7863):326-9.

2. Parker S, Johnson-Lawrence V. Addressing trauma-informed principles in public health through training and practice. Int J Environ Res Public Health. 2022 Jul 11;19(14):8437.

3. Key KD. Expanding ethics review processes to include community-level protections: a case study from Flint, Michigan. AMA J Ethics. 2017;19(10):989-98.

4. Flint Water Advisory Task Force. Flint Water Advisory Task Force final report. 2016 Mar. Available from:

    https://www.michigan.gov/documents/snyder/FWATF_FINAL_REPORT_21March2016_517805_7.pdf

5. Sadler RC, Hippensteel C, Nelson V, Greene-Moton E, Furr-Holden CD. Community-engaged development of a GIS-based healthfulness index to shape health equity solutions. Soc Sci Med. 2019 Apr;227:63-75.

6. Ruckart PZ, Ettinger AS, Hanna-Attisha M, Jones N, Davis SI, Breysse PN. The Flint water crisis: a coordinated public health emergency response and recovery initiative. J Public Health Manag Pract. 2019 Jan/Feb;25(Suppl 1):S84-S90.

7. Brackbill RM, Thorpe LE, DiGrande L, Perrin M, Sapp JH 2nd, Wu D, et al. Surveillance for World Trade Center disaster health effects among survivors of collapsed and damaged buildings. MMWR Surveill Summ. 2006 Apr 7;55(2):1-18.

8. Landrigan PJ, Wilcox KR Jr, Silva J Jr, Humphrey HE, Kauffman C, Heath CW Jr. Cohort study of Michigan residents exposed to polybrominated biphenyls: epidemiologic and immunologic findings. Ann N Y Acad Sci. 1979 May 31;320:284-94.

9. Gilmore B, Ndejjo R, Tchetchia A, de Claro V, Mago E, Diallo AA, et al. Community engagement for COVID-19 prevention and control: a rapid evidence synthesis. BMJ Glob Health. 2020 Oct;5(10):e003188.

10. Epic Systems Corporation. Epic [software]. Verona, WI. Available from: https://www.epic.com/software

11. Sateren WB, Trimble EL, Abrams J, Brawley O, Breen N, Ford L, et al. How sociodemographics, presence of oncology specialists, and hospital cancer programs affect accrual to cancer treatment trials. J Clin Oncol. 2002;20(8):2109-17.

12. Shavers VL, Lynch CF, Burmeister LF. Racial differences in factors that influence the willingness to participate in medical research studies. Ann Epidemiol. 2002;12(4):248-56.

13. Durant RW, Wenzel JA, Scarinci IC, Paterniti DA, Fouad MN, Hurd TC, et al. Perspectives on barriers and facilitators to minority recruitment for clinical trials among cancer center leaders, investigators, research staff, and referring clinicians: enhancing minority participation in clinical trials (EMPaCT). Cancer. 2014;120(S7):1097-105.

14. Webb FJ, Khubchandani J, Striley CW, Cottler LB. Black–White differences in willingness to participate and perceptions about health research: results from the population-based HealthStreet Study. J Immig Minor Health. 2019 Apr;21(2):299-305.

15. Gluck MA, Shaw A, Hill D. Recruiting older African Americans to brain health and aging research through community engagement: lessons from the African-American Brain Health Initiative at Rutgers University-Newark. Generations. 2018 Summer;42(2):78-82.

16. Gaupp-Berghausen M, Raser E, Anaya-Boig E, Avila-Palencia I, de Nazelle A, Dons E, et al. Evaluation of different recruitment methods: longitudinal, web-based, Pan-European physical activity through sustainable transport approaches (PASTA) project. J Med Internet Res. 2019 Mar 9;21(5):e11492.

17. Marmor JK, Oliveria SA, Donahue RP, Garrahie EJ, White MJ, Moore LL, et al. Factors encouraging cohort maintenance in a longitudinal study. J Clin Epidemiol. 1991;44(6):531-5.

18. Murphy J, Brackbill RM, Thalji L, Dolan M, Pulliam P, Walker DJ. Measuring and maximizing coverage in the World Trade Center Health Registry. Stat Med. 2007 Apr 15;26(8):1688-701.

Table 1: Sectors That Were Prioritized for Community Engagement

Faith	Academia	Philanthropy	Parents
Workforce Development	Organized Labor	Media	Youth
Seniors	Non-profit Agencies	Health Care	Law Enforcement
Education	Government	Behavioral Health	Service Delivery
Deaf and Hard of Hearing Community	Hispanic Community	Medical Providers	

Table 2. Definition of Community-Engaged Recruitment Methods

Recruitment Method	Non-Community Engaged	Community Engaged
City-wide mailings	X	
Targeted mailings to lists of people (e.g., Medicaid enrollees, children with blood lead screening during FWC)	X	
Media-News article/Radio/TV	X	
Social Media	X	
Flint Registry website	X	
Co-outreach through community partner		X
Outreach through school/community health worker		X
Public presentations by community outreach team		X
Word of mouth/Community Ambassadors		X

FWC: Flint water crisis

Table 3. Definition of Key Areas of Impact of Community Engagement in Establishing and Implementing the Flint Registry

Key Area	Definition
Accessibility	The strategies used to reduce barriers to learning about and participating in the Flint Registry.
Awareness and first perception	The creation of general awareness of the Flint Registry throughout the community.
Cohort maintenance strategy	The ongoing communication with enrollees and the maintenance of up-to-date contact information.
Community leadership role	The Flint Registry's responsibilities related to connecting with other leaders in the community and sharing the information learned.
Consent process	The process that enrollees used to complete the consent along with details about what should be included in the consent.
Eligibility criteria	The eligibility criteria for enrolling in the Flint Registry.
Enrollment facilitators, barriers, and incentive ideas	The design of the enrollment process and what types of incentives should be provided.
Informatics solutions	The way data are collected and stored using computer software, what software features are included, and which software solutions are the best fit.
Marketing/messaging	The strategies that are included in the overall marketing plan and the messaging that the marketing team utilizes.
Outcome reporting	The design and content of reports that share the outcomes of the Flint Registry work.
Outreach strategy	The strategy for conducting community outreach.
Piloted survey	The participation in the process of completing practice surveys and providing feedback.
Project goals	The goals of the Flint Registry.
Project name, logo, tagline	The design and selection of the project name, logo, and tagline.
Recruitment strategy	The process and details related to locating and contacting potentially eligible enrollees to enroll them in the Flint Registry.
Referral process	The process for making referrals to external service providers.
Referral services	The services that are included in the referral process.
Registry evaluation	Evaluating the process of implementing the Flint Registry and the impact of the work.
Registry leadership	The membership of the Flint Registry leadership team.

Reporting/dissemination	The strategy of sharing information, including the content, the audience, and the priority for reporting out results.
Survey content	The content collected in Flint Registry surveys.
Survey delivery modes	The modes that the Flint Registry uses to collect survey information.

Table 4. Community Engagement Strategies and Key Areas of Impact

Strategy	Role, Membership Size	Key Areas of Impact on Flint Registry
Funded Outreach Partners	To increase the visibility, awareness, and engagement specific to the Flint Registry in the community. Implement overall outreach strategy. *N=7 organizations*	Enrollment facilitators, barriers, and incentive ideas Marketing/messaging Outreach strategy Recruitment strategy
Pediatric Public Health Initiative Parent Partners	Inform and advise on various aspects of initiatives launched by the Michigan State University Pediatric Public Health Initiative. *N=15 members*	Community leadership role Consent process Eligibility criteria Enrollment facilitators, barriers, and incentive ideas Informatics solutions Marketing/messaging Outreach strategy Piloted survey Project goals Project name, logo, tagline Recruitment strategy Referral process Survey content Survey delivery modes
Flint Registry Community Advisory Board	To promote communication between residents, parents, public agencies, schools, and other organizations to facilitate input, increase community awareness, and coordinate activities to benefit those served by the Flint Registry *N=21 members*	Accessibility Cohort maintenance strategy Community leadership role Consent process Eligibility criteria Enrollment facilitators, barriers, and incentive ideas Informatics solutions Marketing/messaging Outcome reporting Outreach strategy Piloted survey Project goals Project name, logo, tagline Recruitment strategy Referral process Registry evaluation Registry leadership Reporting/dissemination Survey content Survey delivery modes

Community Presentations	Communicate availability of Registry and gather community input *N=75 presentations through 2021*	Enrollment facilitators, barriers, and incentive ideas Outreach strategy Referral process
Pre-enrollment Feedback (Through Launch in December 2017)	To provide overall recommendations for the Registry *N=457 comments received prior to launch*	Consent process Marketing/messaging Outreach strategy Referral services Survey content Survey delivery modes
Pediatric Public Health Flint Youth Justice League	To provide a youth perspective and a voice to guide the direction and activities of the Pediatric Public Health Initiative *N=15 members*	Marketing/messaging Outcome reporting Outreach strategy Survey content
Focus Groups	Gathering input from community members on specific questions *N=26 groups, 130 participants*	Awareness and first perception Enrollment facilitators, barriers, and incentive ideas Marketing/messaging Referral services
Community Ambassadors	To communicate the availability of the Flint Registry to the community *N=517 ambassadors through 2021*	Marketing/messaging Outreach strategy Recruitment strategy
Director of Community Engagement and Implementation	Developing new community partnerships and to strengthen existing partnerships *N=1 Director*	Marketing/messaging Outcome reporting Outreach strategy Recruitment strategy Referral services Survey content
Team Members	Recruit and enroll participants, refer to services, disseminate results *N=60 local jobs at Michigan State University in Flint*	Consent process Informatics solutions Outcome reporting Outreach strategy Recruitment strategy Survey content Survey delivery modes

Table 5. Demographics and Social Vulnerability Factors of Adults Who Completed Baseline Surveys through December 2021 (N = 12,404)

Characteristic	Exposed to CER N=5957 N (%)	Not exposed to CER N=5263 N (%)
Age (median) at eligibility	44	50
Gender		
Male	1735 (29.2%)	1749 (33.3%)
Female	4193 (70.6%)	3495 (66.6%)
Other	8 (0.1%)	4 (0.1%)
Race		
Black or African American Only	3891 (67.6%)	2865 (56.5%)
White or Caucasian Only	1560 (27.1%)	1952 (38.5%)
Other	301 (5.2%)	255 (5.0%)
If you lost all your current source(s) of household income (paycheck, public assistance, or other forms of income), how long could you continue to live at your current address and standard of living?		
Less than 1 month	1720 (29.4%)	1431 (27.7%)
1 to 2 months	1301 (22.3%)	1183 (22.9%)
3 to 6 months	627 (10.7%)	553 (10.7%)
7 to 12 months	636 (10.9%)	597 (11.6%)
Don't know	1561 (26.7%)	1399 (27.1%)
Annual Income		
< $25,000	3,291 (60.7%)	2,970 (60.7%)
$25,000-$34,999	645 (11.9%)	627 (12.8%)
$35,000-$49,999	611 (11.3%)	572 (11.7%)
$50,000-$74,999	458 (8.4%)	419 (8.6%)
$75,000+	421 (7.8%)	303 (6.2%)
Education		
Less than HS diploma	651 (11.0%)	624 (12.0%)
HS diploma/GED	1823 (30.9%)	1725 (33.1%)
At least some College	3431 (58.1%)	2864 (54.9%)
Has Medical Insurance		
Yes	5417 (91.3%)	4838 (92.3%)
Do you live in or regularly visit a home built before 1978 that has peeling or chipping paint?		
Yes	1741 (29.6%)	1582 (30.3%)
Number of months from April 2014 through October 2015 lived in the City of Flint?		
Outside City	609 (10.5%)	305 (5.9%)
Resident entire 18 months	4690 (80.6%)	4434 (85.7%)
Resident < 18 months	519 (8.9%)	435 (8.4%)

CER: community-engaged recruitment. N=1,184 enrollees are not included in this table because they did not respond to the survey question about how they heard about the Flint Registry or they selected the response "other" and could not be categorized as CER or non-CER.

FIGURE LEGENDS

Figure 1. Timeline of Flint Registry Community Engagement Activities

Figure 2. Flint Registry Logo and Tagline Designed by Parent Partners and Community

Advisory Board