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# Community Science as a Pathway for Resilience in Response to a Public Health Crisis in Flint, Michigan

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Abstract: While the story of the Flint water crisis has frequently been told, even sympathetic analyses have largely worked to make invisible the significant actions of Flint residents to protect and advocate for their community. Leaving the voices of these stakeholders out of narratives about the crisis has served to deepen distrust in the community. Our project responds to these silences through a community-driven research study aimed explicitly at elevating the frame of Flint residents in and around the Flint water crisis. This paper describes the coming together of the research team, the overall project design for each of the three research efforts, and lessons learned. The three sub-projects include: (1) a qualitative analysis of community sentiment provided during 17 recorded legislative, media, and community events, (2) an analysis of trust in the Flint community through nine focus groups across demographic groups (African American, Hispanic, seniors, and youth) of residents in Flint, and (3) an analysis of the role of the faith-based community in response to public health crises through two focus groups with faith based leaders from Flint involved with response efforts to the water crisis. Our study offers insight for understanding trust in crisis, which could be valuable to other communities and researchers seeking to address similar situations. The project offers community science as a model for considering community engagement in research as part of the process of resilience.

**Keywords:** community-based participatory research; environmental justice; knowledge production; team science; qualitative research

#### 1. Introduction

Since at least January 2016, the Flint water crisis has been a national discussion. Various media outlets, town halls, and televised public forums have occurred, with an effort to gain understanding of the unfolding situation. These efforts resulted in multiple narratives about Flint and its residents. Journalists and researchers from around the country and the world conducted interviews and published articles telling the stories of the Flint water crisis, often from the perspective of a small handful of influential individuals. Although aspects of those narratives are accurate, they are also incomplete and leave out the perspectives, experiences, and actions of Flint community residents (Johnson and Key 2018). Those missing narratives are critical to understanding the totality of the lived experiences of Flint residents.

The genesis of the water crisis is rooted in Public Act 101, which was put in place in 1988 to handle bankruptcy procedures within municipalities across the state of Michigan. This law was expanded and modified over the years, most significantly in 2011 through the Local Government and School District Fiscal Accountability Act, which expanded the powers of emergency financial managers to nearly all decision-making authority within a city. This expanded law was voted down by Michigan residents in 2012 but shortly thereafter the same law, repackaged as the Local Financial Stability and Choice Act, was passed by legislature with an appropriation that would prevent it from coming up for a public vote again (Key 2017). This action created the platform for governor-appointed emergency managers to usurp local authority, thus leading to a loss of democracy in the communities in which emergency managers were appointed.

Beginning in spring 2014, residents in Flint, Michigan, were exposed to toxic levels of lead and other contaminants in their water supply. The contaminants resulted from a series of decisions that left community members unprotected. Of those decisions, two stand out in their impact. First, in response to a threat of cessation of service from the Detroit Water and Sewage Department, leaders in Flint voted to switch to a new water source, the Karegnondi Water Authority (KWA). Given that the new pipeline was not expected to be ready for two years, Flint's governor-appointed emergency manager made the decision to move to the Flint River as an interim water source (Washington and Pellow 2016). In cities across the United States, industry has used rivers for commercial purposes, such as transportation, and dumping of industrial waste. Flint, Michigan, is no exception. Since the 1930s, the local manufacturing industry, including General Motors, DuPont Paint, local dairies, and others have used the Flint River to dump waste from their operations (Butler et al. 2016; Salinsky 2016).

The second major decision that directly harmed the wellbeing of Flint residents arose from the temporariness of the transition from the Detroit water system to the KWA. Michigan Department of Environmental Quality (MDEQ) regulators and Flint engineers decided not to use corrosion control in the treated water because they expected it would take only two years to switch between systems, while several years would be necessary to properly implement an optimized corrosion control treatment plan (OCCT). Implementing an OCCT, which could take over four years, on a system that would last only two was considered to be unnecessary. Lack of corrosion control in the system, combined with highly variable water quality from the Flint River, led to corrosion of distribution system and household pipes, releasing lead, copper, and other contaminants that had accumulated inside the pipes over the years. Within weeks after the water switch, Flint residents complained of foul smells, taste, physical illness, hair loss, and skin rashes (Salinsky 2016; Dixon 2016), but these concerns went unheeded. The dismissal of residents' concerns was particularly upsetting as General Motors' factories in Flint were granted permission to reconnect to water from Detroit Water and Sewerage in October 2014 because the Flint River water was damaging their machines and products.

Soc. Sci. 2019, 8, 94 3 of 25

The well-publicized events of the Flint water crisis changed national discussions about water quality, availability, infrastructure maintenance, and the continued relevance of lead exposure from water. As tends to happen with highly publicized events like those that transpired in Flint, the community was inundated with journalists, scientists, and various individuals claiming in some way that they had unique insight into resolving the city's troubles. Once the public eye shifted to other prominent issues, so too did much of the interest of those claiming they were there to help. Along the way, prominent narratives emerged that elevated the experiences of a relative few over the stories of the vast many in the community. Given frequent incongruencies between the stories of the few with the experiences of many, how the stories of community members get shared has become an important aspect of responding to and recovering from the crisis.

In this paper we describe the efforts of a coalition of community members, community organizations, and academic partners who coalesced around a shared concern for treating narrative as an important aspect of resilience in response to the water crisis. Recognizing that an incomplete or partial narrative can be just as harmful or damaging as no narrative at all, the current work seeks to allow Flint narratives to be told by Flint residents in order to elevate their perspectives, lived experiences, and reactions as they continue to move from crisis to recovery. Our efforts fall along the spectrum of community engagement, as community serves as the driver and equitable partner in unveiling the missing narrative and disseminating it to the world (Key and Lewis 2018). For this paper, we define community to be the residents of the geographic space of the city of Flint, Michigan.

The purpose of this paper is to describe a case analysis of the use of collaborative, community-engaged, team science as a mechanism of community response to a crisis. We argue that both the topic of research (elevating community narratives about the water crisis), as well as the process of research (through community science), are aspects of resilience for the Flint water crisis. The key contributions of this paper include a community-based participatory research (CBPR) approach to interpreting what a *process* of resilience means for a community during and after a crisis. Through a CBPR approach to team science, we propose a new definition for team science that incorporates the transdisciplinarity of team science with the formal and informal educational experiences of community members in the bridged concept of "community science." We offer a model for community-based analysis of data for expressing community voice. Finally, we suggest community science as a potential model for rebuilding trust in the scientific community in the context of violation by experts in a crisis situation.

#### 2. Background Literature

### 2.1. Socially Just Resilience

Given the complex layers of the Flint water crisis, from emergency financial management, racial abandonment, scientific arrogance, and government inaction and direct harm, it is difficult to settle on what it would mean for the city to truly recover from the crisis. Some interventions aimed at supporting resilience in Flint focus on increasing the capacity of individuals to respond to the trauma of the crisis and to use healthy coping strategies when faced with stress and anxiety. Others aim to increase economic opportunities in the city, both responding to direct financial losses during the crisis, such as damage to household plumbing and appliances, as well as implicit financial losses, such as negative impacts on property values. We adopt a holistic understanding of resilience that emphasizes the enhanced wellbeing of the community as an interrelated whole.

As a theoretical concept, resilience has been applied in a variety of fields to refer to the degree to which a pre-existing system can respond to, and recover from, challenges, either through the mobilization of existing resources or through ability to access and recruit external resources. The concept was first introduced to refer to the ability of ecological systems to handle disruptions while still maintaining the pre-existing relationships within the system before the disruption (Holling 1973).

Soc. Sci. 2019, 8, 94 4 of 25

Early approaches to the ecological model assumed that an ecosystem maintained an overall state of equilibrium, which could be returned to after a disruption.

This idea of equilibrium transfers readily over to a generalized notion of "normal" among individuals (within a specific cultural context). Resilience has been a prominent concept within health and mental health scholarship, where such approaches tend to take on an individualistic narrative. In this approach, resilience is understood as a person's ability to handle life stresses without personal or mental health decline (Brown and Kulig 1996). A highly resilient person, within this frame, can adjust to stressors while continuing about a "normal" life. To paraphrase Jiddu Krishnamurti, we ask what it would mean for one to be highly resilient and to be well adjusted to conditions of poverty and racial inequity.

Brown and Kulig (1996) distinguish between individual and collective resilience, such that the former is indicative of an individual's personal autonomy and intent to respond meaningfully to crises, while collective resilience speaks to a community's relational capacity as a system of individuals to adapt to, and mitigate effects of, a crisis. In this vein, Adger (2000) specifies that resilience amounts to a community's ability to respond to crisis without loss of its social infrastructure.

Within disaster research, there has been an important focus on community resilience (Doorn 2017). Disaster management researchers emphasize a socio-ecological approach that does not view resilience as merely a return to an original condition but might also include community adaptation and progression through response to disasters (Doorn 2017). This approach recognizes that no community is fixed in time and expecting a return to a prior condition after the passage of time might actually represent a regression from where a community could have progressed had the disaster not occurred. In communities struggling with poverty and structural racism, a return to a situation before the crisis is often not desirable. In communities like Flint, the crisis that presents acute stressors to the community is rooted in these struggles explicitly (Masten et al. 2016; Pulido 2016; Sadler and Highsmith 2016).

Norris et al. (2008) define resilience not as an outcome, but as the process through which a community is able to engage its resources to positively adapt to a stressor. Little resilience scholarship thoroughly operationalizes, and thus distinguishes, between process and outcome measures (Doorn 2017), with the notable exception of Kafle (2012) who understands process as accounted for through degree of community participation. From an environmental justice perspective, it is vital for community members to participate in decision making processes with respect to rebuilding after a disaster, as community responses to disaster may differ significantly from those proscribed by government officials (Morello-Frosch et al. 2011).

Recognizing that Flint was characterized by pervasive poverty and racialized economic abandonment prior to the water crisis, we understand resilience as a process that begins before official recognition of a crisis event and one that endures long after such recognition has waned. A socially just approach must view the process of resilience as one that aims to improve living conditions beyond their initial state at the recognized beginning of a crisis. This may only be accomplished through the active participation and equal partnership of community members, as only community members can speak to interpreting their own lived experiences and what community enhancements mean for them. We adopt a *resilience social justice* perspective, which emphasizes community access to knowledge as a key dimension of recovery from a community-wide stressor (Comes et al. 2017, p. 1). We extend this approach though an insistence that community members need not only access to knowledge but to also participate in the process of producing knowledge about the community, the crisis, and responses to the crisis in order to truly achieve resilience social justice. More than simply gaining a seat at the table and engaging in the decision-making process about already decided upon "facts", community members must be central to the processes that lead to creating the knowledge upon which community related decisions are made.

Soc. Sci. 2019, 8, 94 5 of 25

# 2.2. Public Engagement

Within the context of disaster, the scientific community plays an important role in analyzing the disaster scenario, understanding what conditions led to the development of the disaster as it unfolded, what actions should be taken moving forward for recovery, and how such situations can be prevented in the future. In the context of the Flint water crisis, the scientific community was slow to respond to the cries of residents to investigate what was occurring with respect to the changes in the water system and experts initially aligned with government officials, minimizing and dismissing residents' concerns. Prominent water scholars sat side by side with public officials at town hall meetings held in Flint and assured community members that the water was safe. In the context of Flint, especially early in the water crisis, scientific experts wielded unfamiliar power to influence public debates about the water system and some relied on their formal expertise rather than informed engagement with community members when they offered their "expert" opinions.

Historically and broadly, the exploitation of power imbalances between scientific researchers and the public has been a significant cause of distrust of scientists by members of the public (Christopher et al. 2008). While responses to such actions have led to the formalization of ethical norms in the practice of research, even today researchers have not developed a sufficient culture of practice that attempts to address and dismantle these power imbalances. For communities of color, unethical practices by scientific researchers, such as the intentional infection of, and failure to treat, African American men and their families with syphilis during the Tuskegee experiment, cast a long shadow on the trustworthiness of scientists (Brandt 1978; Wasserman et al. 2007).

Even research aimed at interventions to improve the lives of low-income communities perpetuates the misuse of power through the extraction of research data from communities without benefit to those communities, assertions that researchers have more valid insights into what is best for the lives of those in the communities they work with than do residents in those communities, the mobilization of resources by researchers to bring about policy outcomes that researchers determine are best for those communities, and the condescending insinuation of a lack of understanding of science, governance, and healthy behaviors on the part of community members (Boulware et al. 2003; Corbie-Smith et al. 1999; Moore 2006). The effect of this unchecked dynamic is further public distrust in, and alienation from, the practice and benefits of scientific research.

A history of failed sustainability of interventions as well as calls for improved equity in research have driven a push towards increasing the participation of members of affected communities in the scientific research conducted about those communities. Participation can vary substantially in form and impact and mere participation does not automatically resolve power imbalances. Power imbalances between researchers and communities, however, are irresolvable without participation of community members.

Sherry Arnstein (1969) proposed a typology of eight levels of participation that are grouped as non-participation, tokenism, and real citizen power. In the lowest levels of (non-)participation, Arnstein said that *manipulation* and *therapy* include participants only to the extent to which the participants can be convinced to adopt a particular understanding. Such efforts emphasize the educating of "uninformed" participants by "informed" scientific experts about the value of the proposed approach. Tokenism encompasses a significant percentage of projects purported to advance participation. From *informing* participants about what their options are within a predetermined set of options, through *consultation* with participants via surveys or public meetings to inform research, to *placation* where a select subset of participants serves in advisory capacity, but with no power to influence the outcome of decision making, the extent of tokenism, for Arnstein, is limited to residents participating in the process of participation. Arnstein's final category of real citizen power includes *partnership*, where participants are involved in negotiation related to accountability and planning, *delegated power*, where participants are leaders in the decision-making process with equal footing as researchers, and *citizen control*, where participants have full control over the direction of the project.

Since it was introduced, Arnstein's model has been highly influential for public policy and research aimed at improving living conditions, particularly in low income communities (Connor 1988; Tritter and McCallum 2006). The ladder model offers a useful heuristic for thinking about how participation is structured through emphasizing that not all forms of participation have the same implications for community empowerment. The model has not been without its critics, who point to the ways in which the model is overly simplistic and suggests a single, linear, hierarchical structure of participation without sufficient attention to the ways in which engagement is developed through various pathways of participation and how quality of engagement affects the potential for community member involvement in decision-making (Carpentier 2016; Tritter and McCallum 2006). For our work, the model is most helpful in understanding the development of the leadership of the research project, but, consistent with Tritter and McCallum (2006), we also find that multiple levels of participation throughout lower rungs of Arnstein's ladder are important in understanding broad community engagement in responding to the water crisis.

# 2.2.1. Community-Based Participatory Research

Currently, the dominant research approach that attempts to move towards citizen control in research is community-based participatory research (CBPR, Baron et al. 2009; Wallerstein and Duran 2010). Developed in the 1990s, CBPR arose within the field of public health as a means of addressing health inequities through acknowledging the ways in which traditional research methods have perpetuated and exacerbated power imbalances and that these imbalances have real implications for the health and wellbeing of vulnerable communities (Israel et al. 1998).

Israel et al. (1998) outlined key principles for community-based research in working towards more equitable and just community-based scholarship. These principles included recognition of the community as a source of identity for residents, recognition and support of existing community networks and resources, facilitation of collaboration throughout all phases of the research, development of knowledge and actions that are beneficial for all research partners, promotion of co-learning and empowerment to address existing inequalities, engagement in a manner that is cyclical and iterative, emphasis on a holistic notion of well-being, and communication of research findings with the participants. Inherent within the CBPR model is an embrace of feminist theory's recognition of multiple ways of knowing and experiencing the world (Israel et al. 1998). Additionally, CBPR adopts a critical social constructionist lens that acknowledges and examines the impact of social institutions and structures on health outcomes, while not rejecting the value of positivistic science in understanding health systems (Israel et al. 1998; Wallerstein and Duran 2008).

In an ideal CBPR study, community partners are fully engaged in the research process, have influence over the study design, methods of data collection, interpretation and influence of results, and ownership of the data. In practice, CBPR may involve community members to varying degrees in the leadership and intellectual development of a research project. While within CBPR the goal is to have community members' involvement integrated throughout the project, the formal allocation of leadership positions, as well as the overall integration of the research team, can differ substantially across projects. Equitable partnership between researchers and community members throughout the research process is a key principle within a CBPR approach (Carcari-Stone et al. 2014).

A commitment to working towards just and equitable systems is a core feature of a CBPR approach (Minkler 2010). In considering communities facing significant burdens related to pollutants, CBPR centers two principle forms of justice (Carcari-Stone et al. 2014). These are distributive and procedural justice. Attention to distributive justice has been a priority within the environmental justice movement and investigations of the distribution of contaminant burdens in marginalized communities have dominated environmental justice scholarship (Bullard 1993; Bullard 1999; Bullard 2005; Hannigan 1995; Martinez-Alier 2003). The findings of a 1987 study commissioned by the United Church of Christ (UCC), published in a report entitled Toxic Wastes and Race in the United States (United Church of Christ 1987), are exemplary of this work. The UCC study showed that race was the most

significant factor correlated with the location of toxic waste facilities, even after controlling for income status. Distributive justice is the notion that low-income and communities of color should not be disproportionately burdened with environmental pollutants (Lake 1996).

Procedural justice considers the ability of marginalized communities to participate in decision-making processes related to the distribution of environmental hazards (Lake 1996). This entails residents in impacted communities having both sustained voice and impact in the development of procedures around how to manage environmental hazards (Minkler 2010). Through the inclusion of residents as decision-makers in the research process, CBPR works towards procedural justice in knowledge creation about topics related to marginalized communities.

# 2.2.2. Citizen Science

Another approach to incorporating the public into science is through citizen science. While some citizen science efforts adopt CBPR or a CBPR-like approach to including the public throughout the research process, other approaches to citizen science can be strictly hierarchical and use the public only in efforts to collect data. Broadly, citizen science involves the use of lay persons in the collection of data to produce scientific knowledge (Pocock et al. 2015). While citizen science efforts are increasingly recognized as a legitimate means for making data collection more cost-effective, inconsistent emphasis has been placed on how knowledge gained can be used and transformed by communities that participate. In recent years, critics have pointed out two generally contradictory aims of citizen science research (Lave 2012; Kinchy et al. 2014; Cooper and Lewenstein 2016). The first approach emphasizes the role of traditional experts and generally does not treat the public as intellectual partners in the production of research knowledge. The second aims to democratize science through a bottom-up approach, wherein the public participates fully throughout the production of scientific knowledge (McCormick 2007, 2009).

For communities struggling with environmental exposures and government accountability, citizen science can lend credibility to activists' claims that have been discounted (McCormick 2012). Citizen science provides access to data that might not otherwise be collected, what Hess (2007, 2009), Frickel et al. (2010), and Woodhouse et al. (2002) refer to as "undone science," on a meaningful time scale (McCormick 2012). At the same time, citizen science approaches enhance the legitimacy of scientific approaches to problem solving, or "scientization," whereas community groups may identify different priorities in resolving community challenges (Eden 1996; Lubitow 2013; Welsh and Wynne 2013; Kinchy et al. 2014; Kimura and Kinchy 2016; McCauley 2017). Kinchy et al. (2014) work shows that most institutionally-led efforts at participatory environmental monitoring do not work to tackle the underlying power structures that lead to environmental inequalities.

While citizen science efforts may include purely community-driven and independently conducted research studies, because there exist dual traditions within citizen science, the concept is somewhat muddied. Further, a danger lies in referring to projects as citizen science when clarity is not provided on which approach a research team is taking and inherent power dynamics between researchers and participants may go unacknowledged (Balazs and Morello-Frosch 2013). If community members are expecting equitable partnership in a citizen science study when academic scientists are expecting residents to provide only on-the-ground labor for collecting samples, conflict between community members and academics may develop. For these reasons, we make power relationships explicit in our work and avoid labeling our work as citizen science.

## 2.3. Transdisciplinarity

# 2.3.1. Team Science

While CBPR methods often adopt a transdisciplinary approach, the specific organizational model for the research described in this paper draws from a team science model. Throughout the process of research, we have been deliberate in our transdisciplinary approach and have felt that the nature

of the work in the Flint community in the context of the water crisis drives the development of new methods of engagement, collaboration, and research analysis. Team science aims to address questions around complex problems using a collaborative and transdisciplinary model (Stokols et al. 2008). "Transdisciplinarity, as distinguished from multidisciplinarity and interdisciplinarity, requires that researchers invent new science together by exploring research questions at the intersection of their respective fields, conducting joint research projects and 'developing methodologies that can be used to re-integrate knowledge'" (Gray 2008, S124). A team science model is generally used in academic, government, and industrial research settings to address large and complex problems. While the transdisciplinary approach within team science assumes the creation of new methods to tackle difficult problems, the institutional foundation of team science limits the degree to which power can adequately be addressed.

The field of team science is emergent (Stokols et al. 2008) and it has yet to make adequate space for incorporating publics as potential team members (Wallerstein et al. forthcoming). This challenge may be in part definitional, as although team science broadly shares a commitment to solving complex problems through transdisciplinary approaches, some science of team science scholars only include teams in their analyses when they have more than 50 investigators or research awards greater than five million dollars (Stokols et al. 2008). Few would deny that poverty and racial problems in the context of environmental justice struggles are indeed complex, but rarely will even large research teams working on these topics enjoy multimillion-dollar research awards.

Tebes (2018) advances participatory team science, which aims to incorporate members of the public into team science research teams. Within this approach, teams are said to be both "bridging" between disciplines and "navigating" across the differing world views of scientists and the public (Tebes 2018, p. 14). Tebes (2018) argues that a key difference between CBPR and participatory team science is that while they both value equity, shared power, and public expertise, in a participatory team science model public stakeholder input does not need to be incorporated throughout the entire research process unless it is clear that at a given research phase it will offer an important scientific contribution.

# 2.3.2. Community Science

Since our work explicitly expects community members to be engaged at every stage of research, we cannot describe our work as participatory team science. Given the lack of space created for community collaboration within the team science model, we develop our own concept to bridge across team science and CBPR. We build on the team science model by re-appropriating the term "community science" from community psychology in order to emphasize the significance of community members within the research team and to generally ground the research team in the community in which it is engaging.

In the academic literature, "community science" comes from social psychology. The term has been used to describe the practical application of science education to the communities in which the education is taking place (Adams 2012). It has also been used to juxtapose the emphasis of psychology on individual wellness as opposed to collective mental well-being within a community context (Wandersman 2003). This approach works to recognize individuals as members of communities and to see research and practice as integrated within a community setting (Kloos 2005; Tebes 2005). Carr (2004) treats community science as an umbrella term over citizen science and civic science, where community science broadly incorporates community publics into conducting research. While we support this development, we suggest that it is premature, because as we previously discussed, there is no inherent imperative for co-leadership and co-production of knowledge within a citizen science model, which we believe must be intrinsic to community science.

Drawing from team science and CBPR, we understand a community science approach as bringing together a transdisciplinary and supra-institutional collaboration of different groups (such as academic partners and government agency representatives), including an essential core of independent community members and representatives of community groups. We define community science as

a collaboration of these partners collectively operating through a team science model. We envision community science as extending beyond this model by emphasizing a community orientation over an (academic) institutional frame in order to address community member questions, analyze community-based study findings, and share an intentional community framed perspective on the interpretation of the research. We aim through this framework of community science to achieve true *resident control* in the conduct of research on communities.

Community science shares similarities with popular epidemiology, which is a process through which members of a community systematically collect information about a perceived health experience and mobilize scientific knowledge and resources to document a relationship between environmental hazards and health outcomes (Brown 1987). Brown (1997) argues that popular epidemiology consists of both gathering and organizing health data so as to address community concerns, as well as engaging in social movement action to move political communities to address perceived harms. Popular epidemiology builds from, and responds to, the traditional epidemiologic model, and therefore typically emphasizes health focused research. Additionally, popular epidemiology does not incorporate a specific model for ongoing public decision-making in research. For instance, community members hiring an independent research team that simply reported back without community member engagement in the research design, data collection, and analysis, could still be considered popular epidemiology.

As a research approach, community science creates a space for theorizing the domain of community-driven research. While CBPR outlines important principles that draw attention to power between researchers and community members, CBPR does not strive to shift research control entirely to communities. Instead, CBPR emphasizes equity between researchers and community members, bringing community members to a shared space of decision-making and control. Parallel to classic resilience literature, CBPR asserts a kind equilibrium between community members and academic researchers through shared power. In our research process, we center community/non-community as the core metric for organizing and understanding community-driven research. This contrasts with an approach that centers academia through an academic/non-academic distinction.

# 3. Team Leadership and Organization

Aligned within Arnstein's model, we aim to achieve full citizen control through leadership by community members, whereas non-community academic partners serve in a more consultative capacity. We modify Arnstein's model by emphasizing *residents* rather than *citizens*, as the language of *citizen control* suggests an exclusive and formal relationship with the state that cannot and should not be assumed. As immigration status varies across the community and specific criminalization techniques of government work to strip and deny the rights of citizenship, we prefer the language of *resident control* as more inclusive and reflective of our work.

The project was initiated by Dr. Kent Key, a Flint resident and a public health researcher who received his doctoral degree in public health. We make this point to counter the assertion that residents in low-income communities lack education and expertise, which tends to be reserved exclusively for the academic partners in research. Academic/non-academic distinctions make invisible the possibility that community members might be academically affiliated or have scientific expertise and credentials. Members of the research team vary broadly in their educational background, with some of the non-academically affiliated community partners holding advanced degrees, having significant experience in research projects over multiple decades, and having professional work responsibilities. Our team is additionally composed of members who do not have advanced academic training yet bring significant informal educational experience and wisdom through their lived experience in the community, which we recognize as just as important in working through analysis and policy recommendations for the Flint community.

We draw from university affiliated researchers with social (sociology, criminal justice, environmental science, and policy) and health science appointments (pediatrics and public health),

academic staff in health sciences, behavioral health, and community engagement, and community partners involved with faith leadership, community research and ethics, community empowerment, and youth services. Project implementation was primarily directed by Karen Calhoun, a Detroit native. During the early stages of these collaborative efforts Calhoun was a community research liaison, or Clinical Research Associate (CRA) for Detroit. Later during the project period, she advanced to Community Engaged Research Program Officer with Michigan Institute for Clinical and Health Research (MICHR) at the University of Michigan (UM).

Decision-making for this project was set up through a deliberative democracy process. While definitions of deliberative democracy vary, at their core they assume a collective decision-making process by affected groups who agree to be intentional about gathering, hearing, and working through and across divergent perspectives (Elster 1998, p. 8). For our group this included the establishment of norms for participation, frank and open discussion about the impact of racism on the community and its relevance in project leadership and planning, and the expectation of regular attendance in in-person, online, and phone meetings by team members. Deliberative democracy often includes advocacy and action for policy improvement (Smith 2003). Project recommendations will initiate a call-to-action to help rebuild trust in the community.

Often in collaborations, "majority rule" is how project decisions are made. However, in this collaboration it was agreed that decisions would be made by consensus, or an "if you can live with it" rule. This meant that if a member of the team did not feel that they could live with a decision, then the team would work together to find a way to help all members to reach at least a feeling that they could live with the decision of the team. The process we followed was modeled on one developed and used by the Detroit Urban Community-Academic Research Center. It helped our team trust that all opinions and feelings were being considered and weighed equally among the team. In this way, decisions to reach consensus did not have to be enthusiastically celebrated by all team members but all members of the team felt comfortable that a fair decision was made by the group.

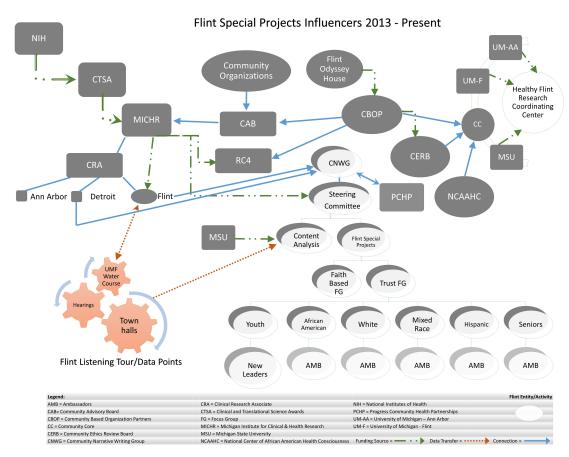
# 4. Research Projects

In developing research that seeks to mobilize community narrative as a means through which to heal and respond to the events of the water crisis, our process was embedded in pre-existing social networks and prior research efforts. Since our research efforts began with a deliberate stage of listening, the development of the project efforts grew iteratively. In the following sections, we describe the development of the various stages of our research. Because academic writing abstracts in an effort to generalize, it tends to make invisible the contributions of community members and the relationships that were essential to build trust in partnerships. In order to show connections in the development of community-driven research, we feel it is necessary and important to include the names of contributors to the work as they are relevant to how the projects coalesced. Given the complexity of this work and the numerous people involved, we are still unable to fully show all of the actors who contribute to the work.

In Figure 1 we show the key influencers that contributed to the development of the research projects as they unfolded, as well as the primary components of our research design. Key influencers provided financial support and social capital allowing for the development of the research projects for the team. Importantly, the figure does not show a snapshot in time but a compressed historical set of configurations that were essential to the successes of research team. For instance, E. Hill De Loney's involvement with Flint Odyssey House preceded the development of Community Based Organization Partners (CBOP). The efforts of Flint Odyssey House along with additional organizations and well-established social connections across the community helped to lay a foundation for the later work of CBOP, and thereby also the work of the Community Ethics Review Board (CERB). The team's research outputs evolved from the Community Narrative Writing Group, which supported the development of the Steering Committee. The Steering Committee oversaw all of the research efforts,

including the content analysis process, which informed the "Flint Special Projects" research efforts, specifically the Faith-based and Trust focus groups.

The faith-based project was determined exempt by the University of Michigan's Health Sciences and Behavioral Sciences Institutional Review Board and Michigan State University's Human Research Protection Program. The trust research project was approved by the University of Michigan's Medical School Institutional Review Board (primary) and Michigan State University's Human Research Protection Program (secondary). Youth participants in the trust project were in or had completed high school, provided with consent forms, and had parental consent for youth participation in the focus groups. No IRB approval was needed for the content analysis project, as these analyses made use only of public documents, and so by definition did not include human subjects.



**Figure 1.** Principle influencers leading to the development and success of the Flint Special Projects research team. In dark grey bubbles we show the community context and influencers to the development of the Flint Special Projects efforts. In light grey ellipses we show the components and derivatives of the Flint Special Projects' research efforts.

## 4.1. Listening to Community Experiences

As the Flint water crisis unfolded, it was apparent that certain voices were being elevated over others. What quickly emerged was a "hero" narrative that suggested only a few individuals were responsible for the successes of community resistance in Flint and that their actions were set against only a vague backdrop of heated town hall meetings and protests. As media furor brewed with accusations and erasures sweeping across academic and political circles, residents in Flint continued longstanding practices of organizing to elevate their own stories and attempting to direct the construction of knowledge and information about their own community and personal experiences.

Flint resident and Deputy Director of CBOP, Dr. Key, was part of a collective of community mobilizers interested in changing narratives about Flint from deficit- to asset-focused. Grounded in his doctoral studies in public health at Walden University, Dr. Key's work focused on improving access to community development resources, such as educational and employment opportunities for young African American youth in Flint. Dr. Key was employed at the MICHR as a CRA for Flint, which positioned him as a community liaison for public health research in Flint as the water crisis began.

As they noticed changes in the water and new health problems, Flint residents reached out to academics to investigate residents' concerns about the quality of the water after the switch from the Detroit system to the Flint River; however, few academics responded that they were willing or able to provide immediate assistance to look into any emerging issues. In early 2016, George Mashour, Director of MICHR, who was away on sabbatical when the first requests for assistance were made, met with community members who were leaders in coalition building in Flint to hear their concerns and needs upon his return. In attendance at this meeting were Rev. Dr. Sarah Bailey and E. Hill De Loney, both Flint residents active in moderating scientific research to ensure ethical engagement with the Flint community. During this meeting, residents requested that MICHR dedicate resources and infrastructure in the form of a "community-engaged research fellowship" for Dr. Key to focus on the needs of the Flint community during the water crisis, support for conducting community-engaged research told from the community's perspective, and resources for community training. Through Dr. Mashour's discretionary funds, MICHR provided \$50,000 for special projects research and \$15,000 for faith-based and academic partner educational programming. This enabled Dr. Key to focus only on assessing community needs by listening to community members as they voiced their concerns through town hall meetings, community meetings, and other gatherings. In all, he attended dozens of gatherings while also hearing community member perspectives through living in Flint and having family members and broad social connections in and around the city.

Out of these initial listening sessions, three linked research projects were ultimately developed by the research team. The first project was a community narrative group that focused on analyzing the stories of Flint residents as they were shared in seventeen public meetings during the water crisis. The community narrative group was established to ensure that narratives about the Flint water crisis and residents' lived experience during the water crisis were gathered from the actual residents in Flint. This concern was due to the fact that Flint had been inundated with researchers and reporters, and, as a result, a number of publications and stories were being disseminated that were written by people outside of Flint. The Healthy Flint Research Coordinating Center (HFRCC) was established specifically to centralize and manage the influx of researchers to the community. In public meetings, community members conveyed the importance in telling their own story.

The other two projects evolved from the analysis of the first project, which inspired a series of focus groups with different groups in the community. The demographic characteristics of focus group participants are shown in Table 1. As shown in the table, the gender distribution for our sample roughly matched the gender distribution in the city. Our focus groups oversampled for African Americans in Flint. In our analysis for this paper, we focus on the evolution and development of these projects through the process of mutual listening, collaboration, and shared leadership as a mechanism of responding to, and recovering from, the violations of trust and power experienced during the water crisis. Our intent in this paper is to emphasize this process of research development instead of the specific results from each of the projects, which will be shared in future papers focused on the topics of those projects.

**Table 1.** Characteristics of participants in focus groups alongside available community characteristics for the city of Flint, Michigan. Community characteristics data are provided from the 2013–2017 American Community Survey (ACS) 5-Year Estimates.

		N in Sample	% in Sample	% in Flint
Gender	Male	73	51.8	48.0
	Female	67	47.5	52.0
	No Response	1	0.7	-
Race	African American	111	76.6	53.9
	White	28	19.3	39.9
	Other	6	4.1	6.2
Employment	Employed	66	50.8	-
	Not Employed	50	38.5	22.2
	Retired	12	9.2	-
	Other	2	1.5	=
Education	Not a HS graduate	41	32.8	16.0
	HS graduate	33	26.4	34.9
	Some college	22	17.6	37.2
	Associates Degree	7	5.6	**
	Certificates	2	1.6	=
	Skilled labor	1	0.8	-
	Bachelor's Degree	9	7.2	11.9
	Advanced Degree	10	8.0	=
Length of Residency	Less than 1 year	4	3.8	=
	1 to 5 years	15	14.2	-
	10 or more years	29	27.4	-
	Lifetime	58	54.7	-

Note: \*\* ACS data for "Some college" and "Associates Degree" are combined.

# 4.1.1. Community Narrative Representation

As scientific interest in Flint increased, community members who had been engaged with community-based participatory research for nearly thirty years worked to establish systems of scientific accountability. Community-Based Organization Partners (CBOP) originated in Flint as an outcome of the W.K. Kellogg Foundation Community Health Scholars Program, which provided funding for early CBPR research efforts in Flint in the 1990's. CBOP sustained as a coalition of Flint residents and community organizations who sought to take a more active role in the administration of public health research and interventions in the Flint community. In early 2016, CBOP partnered with Michigan State University (MSU) and the University of Michigan (UM) to form the HFRCC, which would serve as a clearinghouse for research in Flint (in particular related to the water crisis) and would also direct interested researchers to Flint's CERB (founded by Dr. Kent Key) to get community approval, provide input on proposed research, and ensure community-level benefits and protections (Key 2017).

Karen Calhoun, a CRA for Detroit at MICHR who served on the editorial board for the Progress in Community Health Partnerships journal, solicited the journal's editor and a few associate editors to consider what role the journal could take in responding to the water crisis. From this inquiry, a group of interested academics, including Dr. Key and Mrs. E. Hill De Loney, organized to investigate community voice in the water crisis. The group recommended conducting a content analysis of

community voice to document residents' perspectives on the crisis and prepared an interview guide for interviewing residents. While these interviews were ultimately not completed due to shifting group composition and priorities, the group's efforts helped to organize conversations around how to get at residents' perspectives on the water crisis. Simultaneously, community and academic researchers interested in telling stories from the community's perspective coalesced around the work that Dr. Key was organizing. Initially, this coalescence was aimed at bridging distinct ongoing projects investigating the water crisis and the group was identified as a community narrative writing group.

Later in 2016, Joseph A. Hamm, an assistant professor of criminal justice and environmental science at MSU, met Rev. Dr. Bailey after an MSU meeting for researchers with an interest in the Flint water crisis. Rev. Dr. Bailey invited Dr. Hamm to a community meeting where he met Dr. Key. Dr. Hamm shared his theoretical hypothesis regarding a complex hierarchy of constructs within the "trust crisis" that was widely acknowledged as having developed across the city. From these discussions, and based on his expertise in topics related to trust, Dr. Hamm was invited to join the narrative writing team.

In fall 2016 at the annual meeting of the American Public Health Association, Jennifer Carrera and Dr. Key reconnected after having co-presented on a panel during the University of Michigan-Flint's Flint Water Course in January 2016. The Flint Water Course was a course sponsored by the University of Michigan Flint that focused on the water crisis, offered course credit for students, and was free and open to the public. Dr. Suzanne Selig, then Director of the of Public Health and Health Studies, recruited E. Yvonne Lewis, Dr. Kent Key, Mrs. Kay Doerr, and Mr. Mark Valacak to form the initial team for developing the Flint Water Course. This team invited experts from various fields—Public Health, Medicine, Engineering, Water Experts, Community Leaders and Residents, Policy Makers and Legislators, School Systems, Social Workers, Philanthropy, Faith Community Leaders, and others—to share critical information and provide a platform for residents to voice and speak their experience. This course was facilitated by the team and recorded and archived on YouTube. One key driver for the creation of this course was the fact that many residents wanted and requested a place where they could gain information they could trust.

During much of 2016, Dr. Carrera was focusing on analyzing discourse production related to Flint. While tasked as an environmental justice scholar at MSU, with the sudden expectation of being an "expert" on Flint, Dr. Carrera declined to initiate a new project directly impacting Flint residents so as not to further community exploitation within the crisis. Instead, she worked to organize copious publicly available documents produced by journalists and researchers in order to understand how discourse shaped narratives about the Flint community. She listened to residents when invited to speak and stated that she was available if community members felt she could be helpful. This approach drew Dr. Key's attention and Dr. Carrera was invited to participate in the community narrative writing group.

Commitment from participants in the writing group waned as planned projects either were published (Johnson and Key 2018) or shelved for other priorities. Over the next year the community narrative writing group evolved from a group of distinct ongoing projects to a single collaborative research team. Conversations within the group's core members turned to how to analyze the public testimonies of residents who had spoken at the numerous public meetings held in the community. Thus emerged the first major project of the research team, investigating "what priorities and connections did Flint residents express during the water crisis and how did these priorities diverge from popular narratives of the crisis?"

The community narrative project collected seventeen publicly available recordings from meetings representing key community, legislative, and media events held between January 2016 and December 2016. This activity was critical in that many of these events recorded experiences directly from residents, policy makers, health professionals, and other stakeholders. More importantly, they included the mis-steps, mis-information, lies, and breakdown in efforts to protect the community residents of

Flint. They also indicated some of the experiences of Hispanic residents during the beginning of the water crisis.

As none of these meetings had available transcripts, using funds from an internal MSU award to Dr. Hamm (entitled: Trust in the Shadow of Flint), the team hired a Flint resident to transcribe the recordings. Each transcript was distributed to two team members for coding and analysis. The research team reviewed the transcripts to identify initial themes, which were organized in an initial codebook of nine themes: community, communication, inequality, health, money and finances, pipes and infrastructure, politics, trust, and water distribution. The team agreed to code via consensus coding, wherein the collective research team would discuss and agree on definitions of themes in order that they would be included in the codebook. The team met in person to discuss the initial themes, then transcripts were reviewed again to refine themes and identify additional themes. The codebook was updated to reflect changes to the themes. The transcripts were reviewed again to code for all of the themes the group had added to the codebook. After completion of the codebook, the team met to collectively discuss and analyze the supporting transcript statements to identify relationships across themes as identified by Flint residents.

# 4.1.2. Trust within Diverse Populations

Across community meetings, a consistent theme of distrust emerged. Throughout the water crisis, residents increasingly felt like they were unsure of who and what they could trust in order to keep themselves and their families safe. Loss of trust in government institutions was spurred by institutions that were supposed to protect the wellbeing of the community failing to uphold those responsibilities. Specific political figures and officials were revealed over time to have taken direct actions that were against the wellbeing of the community in favor of protecting those officials' employment status or to simply reduce the costs of governing. In a community that had steadily lost confidence that officials would listen to community needs and desires under emergency management, the events of the Flint water crisis only exacerbated these tensions.

Further, the Flint water crisis broadened this distrust to the scientific community. This was due in no small part to the general disinterest that the academic community met with residents' concerns early in the crisis and that scientific experts initially sided with government statements, assuming the general trustworthiness of officials over the claims of the people. This contributed to a commonly held feeling by residents that academics exploit the vulnerabilities of low-income communities, particularly those of color. The Tuskegee Study lingers as an acute example of this violation in many Flint residents' minds.

While lack of trust was a common sentiment across the community, notions of who could be trusted and partnered with varied within the community. These sentiments seemed to vary with consideration to age, religious affiliation, and racial identification. As apparent lack of trust was recognized within and outside of the Flint community, broad questions remained about how, and whether it might even be possible, to restore trust in institutions and public figures.

The second major project of the research team investigates "what issues related to trust regarding the water crisis did Flint residents identify and how did these insights differ across different populations within the community?" To investigate trust within the Flint community, our research team considered how demographic groups might have varying experiences with trust in different entities. Using purposive sampling, we identified potential divergent groups as youth, seniors, African-American, white, mixed race, and Hispanic. For each of these demographic groups, the research team set out to conduct focus groups to better understand that groups perspectives about the water crisis and trust in the community.

Youth were chosen as a subpopulation because while they are particularly vulnerable to physical harm caused by lead (Harlan et al. 1985), few investigations had engaged with youth about their own perspectives about the water crisis. IRB approval was granted for youth as young as 14, who would have been 9–10 years of age at the time of the initial water switch. Seniors were actively engaged in community meetings about the water crisis, yet few narratives focused on the specific needs of seniors

either. Flint is discussed as a majority African American community, and while this is true, Flint is 54% African American and 40% white (U.S. Census Bureau 2017). We felt it was important to consider the perspectives of African American residents as well as white residents in their framing of the water crisis. While we intended to recruit for focus groups that were African American, white, and non-specified, in the actual focus groups we ended up with mostly African American residents and some residents that identified as multiple races, including African American. We accept that these focus groups in the end do not allow us to conduct a distinct racial analysis but instead represent primarily African American, adult residents of Flint, which represent the majority population in Flint. Finally, we opted to include an Hispanic focus group session because Spanish speaking residents were largely ignored during the water crisis, only receiving properly translated materials from media outlets trusted by the community a year after letters went out to English speaking Flint residents. The 2013–2017 American Community Survey 5-Year Estimates indicate that 3.9% of the Flint population identifies as Hispanic.

All participants received \$50 and a free meal for participating in the focus group. Recruitment exceeded the expectation of the research team, and at times the team had to turn interested residents away. The majority of interested residents that were turned away were able to be accommodated by additional sessions or other research efforts. There were 45 participants in four youth focus group sessions, 30 participants in two senior focus group sessions, 15 participants in one African American focus group session, 30 participants in two mixed race focus group sessions, and 16 participants in one Hispanic focus group session.

For the analysis of the focus group session data, we adapted a model established by an earlier community engaged research effort, the RC4 project (U.S. Department of Health and Human Services 2018). Prior to the water crisis, MICHR received funding from the National Institutes of Health (NIH) to work with the CRAs to conduct community-engaged research into issues related to trust and research across predominately African American populations in Southeast Michigan. The "Enhancing Community/Academic Clinical Research Collaboration", or RC4 project as it was called, explored trust in three communities (Flint, Detroit, and Washtenaw County and Ann Arbor) to facilitate collaboration between academic health centers and community-based organizations for health science research. Two to three focus groups were held in each community to get an understanding of communities' perceptions of research and what it takes to get underrepresented communities to be more involved with community-engaged research.

The RC4 process developed a model for qualitative data analysis that served as a model for engaging community partners in the data analysis process projects, as described in this paper. In the RC4 project, identical questions were asked across each community. An evaluation specialist at UM identified themes within each transcript, and then cut the themes out into separate segments of text. These text segments were then discussed in a collective meeting with the data analysis team.

Building from the model established in the RC4 process, the projects discussed in this paper aimed to increase participant engagement in the research process by also including participants in data coding. Unlike the RC4 process, in this project the research participants, rather than an evaluation specialist helped to identify key segments of text. One to three participants from each focus group, were invited to serve as Ambassadors who would participate in the data analysis process, help to code the transcripts, and assess whether the transcripts and coding process accurately reflected the content and intent of the discussions during the focus group sessions. Adult Ambassadors received \$150 to participate in the data analysis process. The youth Ambassadors received \$250, because in addition to the data analysis process, the youth were also invited to assist with other aspects of the project to learn more about the research process and to encourage mentoring. These youth were referred to as New Leaders by the research team.

Participants invited to engage in the data analysis process were asked to read the transcript of the session they participated in and identify important sections of text that they felt conveyed a meaningful theme. The research team also reviewed the transcripts for significant statements made by participants. At a large meeting of data analysis participants and the research team, the group organized the

transcript cut-outs into themes and then discussed as a group how the cut-outs represented specific concepts and how those concepts were interrelated with each other. The themes were organized according to nine codes identified during the narrative group's coding of seventeen transcriptions of publicly available recordings of community, legislative, and media events. This process followed a procedure of consensus coding for collective analysis of significant insights from the transcripts, resulting in a concept map.

# 4.1.3. Faith-Based Community as Public Health Leaders

A second significant theme across community meetings was the important role that faith-based leaders played in Flint during the water crisis. In the context of pervasive mistrust across the Flint community, by and large residents turned to figures within their community who had established and maintained trust through participating in the daily lives of community members. These figures predominantly included various clergy, as well as leaders of non-profit organizations. In particular, clergy expressed that they had been tasked with the expectation to not only serve their congregations' spiritual needs but their public health needs as well, for which few felt adequately prepared.

Early in the crisis, information available to Flint pastors varied. Those that lived in the city experienced personal consequences from using the water, such as having itchy skin, and many stopped drinking the water out of caution. Those that lived outside of the city but served congregations within the city often continued using the water and some reported getting sick from drinking the water because they did not realize that there was a problem with it. Pastors struggled with feeling responsible for caring for their congregations and the broader community but not knowing where to get answers to the questions they were posed with. Despite inconsistent information, the faith-based community is recognized as the first group to begin passing out water, well before any official declarations of emergency.

External actors working to address the unfolding public health situation began to recognize the important role that pastors in the community served, but these actors tended to appeal to religious leaders of larger congregations, leaving faith leaders of smaller congregations out of the conversation. In the larger meetings, pastors of smaller congregations often felt like their voices were pushed aside because pastors at large congregations tend to be recognized first by outside groups for the scope of their influence. As the Environmental Protection Agency's (EPA) Environmental Justice team attempted to work with Flint pastors to serve as a conduit for sharing information with Flint residents, this dynamic between large and small congregations made it challenging for concerns of small congregations to be shared with EPA officials.

To provide a stronger voice for smaller congregations and to bring Flint pastors to the table in public health research, Rev. Dr. Bailey and E. Yvonne Lewis formed the informal organization All Faith and Health Alliance (All Faith). Rev. Dr. Bailey invited EPA representatives to the All Faith meetings, where they heard from leaders of smaller congregations about their concerns regarding proposed protocols for lead mitigation strategies and possible compliance issues. Pastors tended to focus on how complex the steps were that EPA officials expected residents to perform in order to test or flush the water. Pastors felt that EPA officials did not have adequate recognition of the competing demands on working, low-income families. Additionally, EPA representatives learned that often pastors serve multiple roles, have advanced degrees, and hold additional jobs in the community. Through listening to the pastors at All Faith, EPA was able to hear these challenges and to provide resolutions for some community issues, such as assisting to overcome regulatory obstacles in setting up mobile grocery stores so people with food stamps can get fruits and vegetables to help with lead mitigation.

With pastors being solicited by local and distant researchers to participate directly in studies and to use their congregations as sample pools, All Faith offered a place for faith leaders of large and small congregations to come together and learn about what research activities were happening in the community, what different kinds of research opportunities were available, and to have a conversation about what kind of research they would like to see happening or participate in.

These conversations, in addition to the collective community conversations about the importance of the faith-based community during the water crisis, motivated this project's research team to conduct a specific analysis on the perspective of the faith-based community during the water crisis. The third major project of the research team investigates "what priorities and connections did Flint faith-based leaders identify regarding the water crisis and how did these insights diverge from popular narratives of the crisis?"

The faith-based project conducted two focus groups with eleven Flint area faith leaders in March 2018. In addition to the focus groups, participants completed a demographic and pre/post trust survey. The team hired a Flint resident to transcribe the recordings. Building on the model established through the RC4 project, these transcripts were coded by the research team, as well as by two participants from the focus groups for validation. The Faith Ambassadors and the research team identified themes from cutouts from each transcript and themes were discussed at a meeting of the research team and the Ambassadors. Themes and connections were identified via consensus coding. Consistent with the process conducted for different demographic groups, the themes were aligned with the content analysis codebook.

#### 5. Discussion

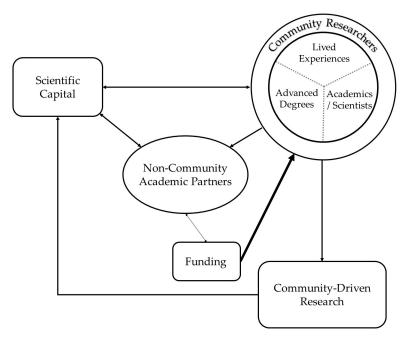
The various components of the projects described in this paper have involved intentional, community-led, and community-driven steps to conduct research on questions of interest to residents, in light of state actions and the work of outside and other researchers, who at worst attempted to silence and at best ignored resident voices and concerns related to the Flint water crisis. Within these collaborative projects, the team came together across sectors of the community, across disciplines, and across institutions in co-leadership of efforts. In addition to co-production of knowledge, through these efforts the projects have prioritized resident control and residents' voices through resident leadership of the community science team, resident Ambassadors in the data analysis process, and listening to residents throughout the research process. Due to constraints imposed from the need to draw from external funding sources and institutional obstacles generated when academic partners are involved, true resident control is rarely if ever achievable. Still, we believe that our community science approach moves us much closer to that aim.

CBPR projects are not limited to low-income communities and some are carried out in partnership with well-resourced individual community-based organizations, sometimes in affluent communities. CBPR becomes more complicated with diffuse community representation in an under-resourced community, such as Flint. Of high importance to this project team was the development and implementation of a CBPR approach that addresses power within the team and between the team and the community, bridging leadership across multiple organizations and community members for shared leadership within the team, and accomplishing this work in a financially-constrained context. We addressed power within the team through the deliberative democracy process and the understanding that non-community academic partners would serve in a consultative and not directive role unless invited by the larger team. Our efforts to address power between the team and the community involved including community members as ambassadors to the data analysis process and working to increase capacity among youth through the promotion of new leaders in public health.

Often under-resourced communities are assumed to be lacking in human capital, which scientists are seen to share with the community through their professional expertise. It is important to recognize that within all communities it should not be assumed that there are not experts who hold advanced degrees and who bring unique and valuable skill sets. Nor should the lived experiences of residents be undervalued in their expert understanding of their own experiences and histories. A strength of this project was the recognition of skills and varied resources of the community, including research skills and community networks that can be, and have been, mobilized as part of the process.

In Figure 2 we substitute community/non-community for the more commonly advanced academic/non-academic distinction. We argue that community/non-community is the central metric

of importance in community-driven research. In this way we show how community members may have academic credentials, advanced degrees or training, or significant lived experience that positions them as experts on their communities. These community members are contributing to scientific capital (knowledge, skills, resources) and continue to gain scientific capital through their engagement in research projects. In community-driven research, non-community academic partners should not be making decisions about the needs and priorities for the community. This model of community science is led by community members, explicitly, with non-community academic partners contributing their expertise and resources to shared scientific capital as general scientific knowledge or collaboratively with communities through serving in a consultative role on community science teams.



**Figure 2.** Community as the key metric for organizing community-driven research. Community researchers include individuals who have lived experiences in the community, advanced degrees and certifications, or who may be academics and scientists. Non-community academic partners are distinct from community researchers in their lack of community identity. Community-driven research may be carried out in partnership with non-community academics, however, community researchers should drive the direction of the research. Funding opportunities can and should come to non-community academics, but funding priorities should emphasize resources provided to community researchers, which we have indicated with a thicker arrow.

Research projects do require resources; within this community engaged process, it has been imperative to put financial resources in the hands of community members to drive the research process rather than given to outside researchers. Traditional science models prioritize grant funded research to individual researchers, but this model inhibits the opportunity for community members to lead research projects and structurally prioritizes the academic researchers' interests. As we found through the direct support of MICHR and Dr. Hamm, in order to be successful and to truly disrupt power imbalances, community-driven research requires direct funding of community science teams. Money should be distributed directly to the community group and should not be preferentially provided indirectly through non-community academic partners and institutions.

The work of this collaboration built upon existing community mobilization efforts already in place. The analysis process for this project builds off of the RC4 process and model. Collaborations were established through significant investments by the academic partners to learn about, and engage with, the community over an extended period of time. The partnership of the academics in the project was through invitation from the team, based on expertise, commitment to working in a capacity that

served the research needs and interests of the community, and prioritizing residents' voices over academics' interests. The meetings held by HFRCC to connect researchers with community members helped to facilitate this process.

Deliberative democracy informed how the team was formed, as well as processes of decision-making. The team was active and intentional in being attentive to who was speaking and who was listening. An implicit assumption held by the project team was that community member voices should be heard first. Academic partners offered their skills in a consultative capacity as equal partners in the research but not as the loudest or first voices to be heard in discussions. Deliberative democracy helped to establish the team's vision of community science resonating with the frames of CBPR and team science. Because of the intentionality with the process, the team saw this approach as a mechanism of resilience through engaging residents as having authority over knowledge production.

In this work, the concept of resident control from community science has dovetailed with contributing to community resilience in that residents have been active participants in the process, and the project team has focused on equal partnerships and consensus building. Additionally, the team has effectively mobilized resources to create opportunities for community participation. For instance, community members were invited not only to participate in focus groups but also to be part of the team analyzing important themes and their meanings from focus group transcripts; community participants were financially compensated for their involvement in the efforts.

A key indicator of the importance of this work for resilience has been the degree of engagement of community members in the research process. Research fatigue was apparent in initial recruitment conversations with key stakeholders who said that they and community members were tired of being involved with research. However, after communicating that the research was being conducted by Flint residents in order to advance a narrative centering Flint residents' voices, most were interested in participating in the research and connecting others who might be interested in being involved with the research team. While the Flint community has been inundated with research efforts and residents do experience research fatigue, this research team had no difficulty in recruiting for focus group sessions. Rather, the team was challenged with having too many participants arrive at sessions. While as many additional participants that could be accommodated were, due to participant payment and funding limits, some did have to be turned away. After focus group sessions were completed, many participants indicated that they were happy to be involved in the research and excited about future opportunities to engage. They asked about other opportunities to participate in the research, from being Ambassadors, to other focus group sessions, or other events, such as town halls, which they could participate in. This excitement stemmed from a sense of hope generated during the sessions that something positive was being done in the community and they could contribute to that process.

The concept of resilience, in addition to some of the aspects of the projects described above, includes responding to and recovering from challenges; in the context of community resilience, this also means the relational capacity of residents to collectively adapt to and mitigate the effects of the Flint water crisis. Faith communities in Flint have mobilized to provide water to residents regardless of city or state (in)action to remedy the inadequate treatment of water and the corrosion of city pipes. While water infrastructure and treatment are not in direct control of residents, residents are able to, and have, mobilized to share their lived experiences in effort to mitigate negative outcomes of the crisis. This is the case even in the context of questioning trust in the city, state, and institutions that have the capacity to resolve issues with the water and respond to community concerns, as those entities have failed to do so in an adequate way to protect the health and wellbeing of community residents.

The project team, as a network of individuals from across the community, has contributed to resilience from the Flint water crisis by connecting residents and creating opportunities for residents' voices to be heard, with consequences for each next step or phase in the project itself. An important caveat, however, is that resilience should not be considered as a set of actions to complete once to "achieve" recovery from challenges, but should be considered as an active, ongoing process. Continuing community engagement in this project, and more broadly including residents through

sharing their stories, having control over their narratives and meanings, and actively participating together, is integral to resilience as a process.

#### 6. Conclusions

The Flint water crisis is an example of a complex system of tragedies held together under the umbrella of crisis or disaster. Most frequently emphasized was the exposure of children to elevated lead levels, which resulted from pipe corrosion. Less often emphasized were all of the other residents, including healthy adults, immunocompromised adults, and senior citizens, who were also exposed to contaminants released in the water. Language presented an additional barrier for some groups as initial alerts went out only in English, while Arabic and Spanish speaking groups were not alerted, either because the information was not translated or the avenues of distribution did not reach those communities.

Flint struggled under emergency management since 2011, which itself developed as a result of sustained economic deprivation that fell along racialized boundaries in the region. Indirect and direct actions by regulators who should have prioritized the wellbeing of the community instead caused active harm and attempted to cover up evidence of this harm. Finally, scientists who should have acted with curiosity and recognized the limits of their knowledge, instead relied on their status as experts when they spoke publicly and in alliance with government officials. The apparent collusion of scientists with government actors led to tremendous loss of trust across the community, not only in government but also in specific scientific actors as well.

Resilience from the Flint water crisis, then, is much more than replacing service lines across the city. Infrastructurally, residents also desire household plumbing and appliances to be replaced, as the failure to care for infrastructure falls squarely on the government entities responsible for providing the water. While Flint is no longer under emergency management, this does not resolve the need for fair distribution of resources across the region and financial resources owed to cities across the state through revenue sharing. Positive change for Flint would require a shift from seeing the community as just poor and instead work towards viewing the community's rich history and resources, including community member expertise in CBPR, as assets. Such efforts would prioritize well-being over economics and would hold accountable those who engage in ways that do not put community well-being first.

Aligned within the approach adopted in this paper, we highlight a critical aspect of resilience for the Flint community, which addresses the loss of trust in experts. Such experts failed in their obligation to be objective and concerned about pursuing an ideal of truth as an ethical obligation of science and as a moral obligation of scientists. In pursuing resilience for Flint residents, scientists must partner with residents to pursue a goal of procedural justice in knowledge production. As demonstrated in this paper, we suggest community science as a mechanism through which trust can be built or reconstructed in shared knowledge production. Future analyses of this work will highlight the specific findings of the research projects. Of particular interest to this team, we intend to examine the hierarchical structure of trust systems in the community and the complexity of lack of trust in institutions that is shared among Flint residents.

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Soc. Sci. 2019, 8, 94 25 of 25

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