

Comment



BRETT CARLSEN/GETTY

Residents of Flint, Michigan, attended community blood-testing events in 2016 after lead contamination was found in the city's water supply.

Community–academic partnerships helped Flint through its water crisis

E. Yvonne Lewis & Richard C. Sadler

A city that faced a public-health emergency shows how collaborations with neighbourhood advocates can advance health equity.

Flint in Michigan is infamous for its water crisis. From 2014, the state government decided to divert the city's water supply through ageing pipes that contained lead, a neurotoxin, making many people unwell and leading to some deaths. Residents were left searching out water that was safe for drinking, washing and bathing. Nine public officials face criminal negligence charges around wilful neglect of duty and for allegedly concealing and misrepresenting data. A US\$640-million class-action lawsuit

is moving its way through the courts.

But Flint should be known for more than its public-health tragedy. Accounts of the crisis often cast pioneering scientists and physicians as lone heroes, assuming that those who documented the lead in the water and blood of Flint's residents were the ones who brought officials to account. That assumption erases the work of community activists who got academics to look for lead and its damaging health effects in the first place. Flint is a working example of how community members and academics can

collaborate on problems – such as how to collect data or develop robust models of health risks and injustices – and on finding solutions.

Flint's water crisis came to light because of strong research partnerships between activists, academics and other specialists. These partnerships continue to advance work that matters to the community. Efforts include identifying neighbourhood conditions (including crime levels, asthma rates and access to healthy food) and assessing projects to improve them. It requires a commitment that research does not just end up in a thesis or paper, but becomes information that is useful to community members.

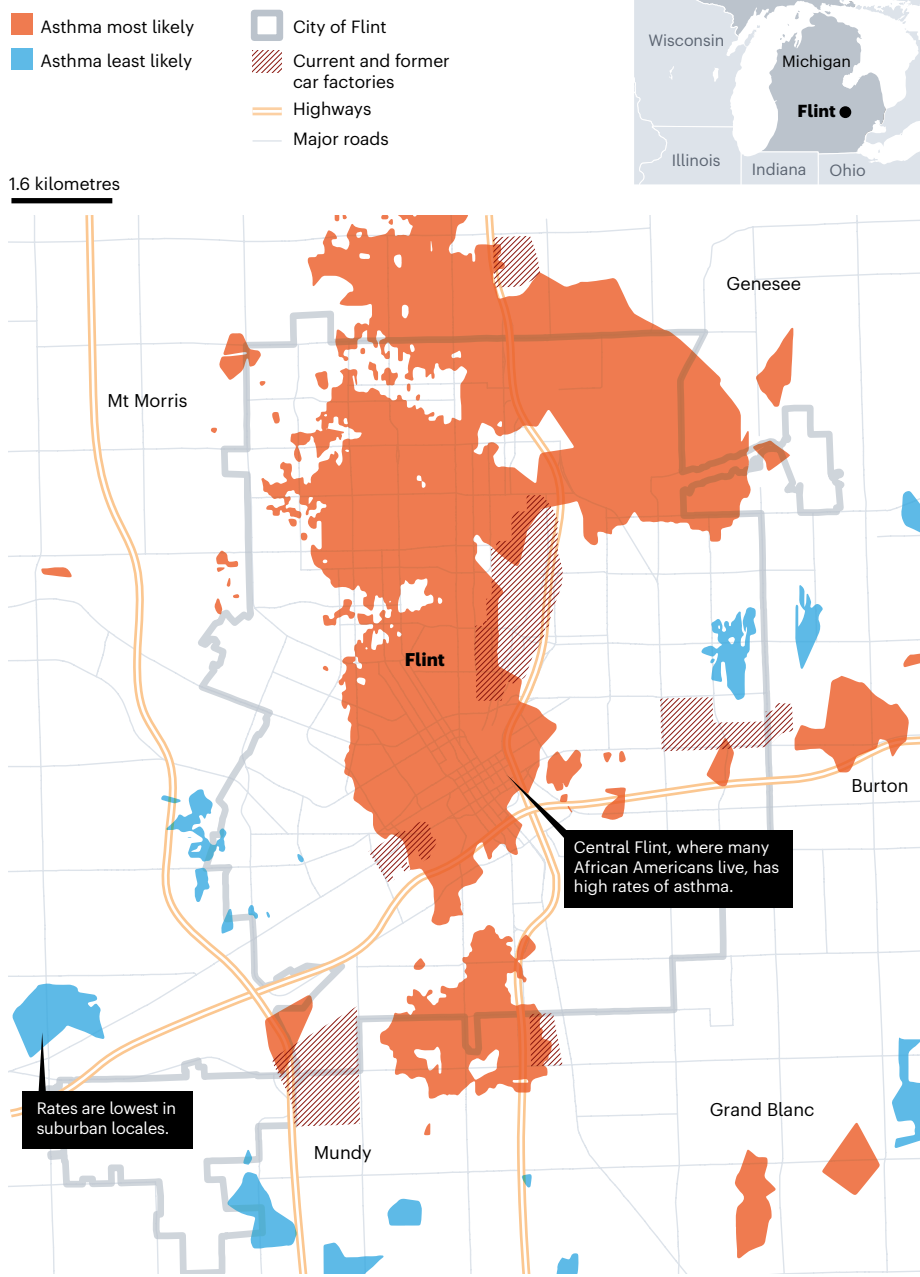
Here's one example. The Genesee Health Plan is a non-profit benefit programme that provides basic health-care coverage to uninsured residents of Genesee County, which includes Flint. It was established in 2001 and is supported by property taxes. One of us (E.Y.L.) helped to provide the other (R.C.S.) with data from a sample of Genesee Health Plan enrollees to produce maps of chronic conditions. One map showed the health plan's wide adoption in our community, and officials used it to advocate for voter support when the tax measure was renewed in 2018. This partnership was possible only because of the connections already formed between E.Y.L., who is a community organizer, and R.C.S., a geographer and public-health specialist at Michigan State University (MSU) in Flint.

Long-standing efforts to ensure Flint community members have a voice in research have gained momentum. One tangible result was the creation of the Healthy Flint Research Coordinating Center in 2016. To form the centre, E.Y.L. and another Flint resident representing community organizations joined up with six researchers – two each at MSU, the University of Michigan in Ann Arbor and the University of Michigan–Flint. It works to minimize redundant research, maximize creation of new community-academic partnerships and ensure that research receives a community ethics review.

Also established in 2016 to support equitable community-academic partnerships was the Flint Center for Health Equity Solutions, funded by the US National Institutes of Health (NIH). E.Y.L. is the centre's overall community principal investigator. Each of its four divisions and two research projects is co-directed by a community member and an academic. The divisions are: methodology (which R.C.S. directs); dissemination and implementation sciences; administrative; and consortium partners. A programme within the centre – in which people with substance-use disorders are

ASTHMA HOTSPOTS IN FLINT

Community-academic partnerships strengthened during Flint's water crisis continue to bear fruit, such as revealing high rates of asthma in some areas. This helps to direct interventions such as mobile health units.



coached by their peers – has expanded and is now supported by additional external funding.

Here, we distil how we've made community-based research work, and provide lessons others might use.

Distinct challenges

Each of us experienced different challenges before we formed our community partnership, which might offer some pointers for others

considering such collaborations. To that end, here, we relate our stories individually.

R.C.S. writes: I grew up in Flint, and joined MSU as a faculty member in 2015. I knew that the kind of community-focused work I was most passionate about makes it harder to rack up the publications and citations required to progress in most academic institutions, which often treat these as a proxy for high-quality research.

I still worked to hit those markers, publishing

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more than 50 papers in 6 years. I secured several grants from agencies that fund research that has community value – including agencies in the NIH, the US Centers for Disease Control and Prevention (CDC) and the Michigan Department of Health and Human Services. My focus was on work that mattered to the community, and I didn't worry whether journals had high impact factors or huge name recognition.

The community-engaged philosophy of the College of Human Medicine at MSU – where I gained tenure this year – made it more open to alternative metrics, such as volunteering on local non-profit committees, conducting community-based mapping and talking about research at local meetings. The key was to frame my academic output on a longer time scale than that of publications – long enough to see meaningful change.

E.Y.L. writes: As an African American female community activist of decades' standing, I worried about being physically mistreated, emotionally abused and misrepresented by research institutions. On one occasion before I moved to Flint, I remarked that some physicians' descriptions of pregnant African American women as unconcerned with or unwilling to take care of their own needs did not reflect people in my community. I was asked about my academic credentials and then ignored for the rest of the conversation. I experienced this often during the water crisis: community members were touted as being great citizen scientists, until there was disagreement with the 'real scientists'. Then we were marginalized and told we lacked the necessary degrees to provide input.

As community members, we also see our ideas appropriated. For instance, during a discussion at one national meeting, I made a distinction – on the basis of my own experience – between projects that were faith-based (driven by religious principles) and those that were faith-placed (using spaces such as churches). The following year, a researcher presented data based on this model without acknowledging me as the inspiration. I felt dishonoured, discouraged and demotivated. I now ask academic partners to give attribution for my ideas. Knowing the norms – and what credit to request – has helped me immeasurably.

Joint challenges

One of the biggest barriers to community participation is language. Words can have different meanings in different contexts – for instance, the phrase 'those people' can be highly offensive in many situations. When community members hear terms such as public engagement, they assume that 'public' refers to a broad, mixed group of individuals, such as those who might go to a public event. Yet academics often use the term to mean targeted outreach to specific groups of people – faith leaders, patient groups or policymakers,

say. And to help navigate excessive jargon in the early stages of Flint's partnerships, one group developed a glossary of acronyms such as NIH and CDC.

Importantly, everyone involved must take time to understand the culture and unique characteristics of the groups within communities. Not all Black communities are the same, for instance, and none is homogeneous. The heterogeneity among people's levels of income, education and health insurance must be kept in mind in communications. Research materials written in English for a 'general audience' might not be appropriate – strong cultural dialects and a lack of access to information need to be considered.

Funding norms can also become a barrier to sustaining long-term relationships. Grants

“The most important ingredient in making collaborations work is commitment.”

that last only one, two or five years are insufficient to address many community concerns. Too many communities have experienced projects for which funding ends and researchers move on, leaving unfinished work. Without sustained effort, the situation can revert to being the same or worse than it was before the project began. This is partly why community-engaged work is so important: researchers committed to the cause will continue as partners long after the funding is gone. And if grants from typical funders run out, academics will find other sources of support for community partners – such as by maintaining relationships with local philanthropies.

(In Flint, such support has come from the C. S. Mott Foundation and Community Foundation of Greater Flint.)

Researchers often come to communities with a prepared study design, seeking approval rather than input – even when input could improve a study. Researchers assessing campaigns to promote healthy eating might include a control group that receives nothing, whereas the treatment group receives a suite of services and vouchers. This creates a perception of unfairness that can warp a study and discourage participation. Too often, researchers treat community partners who point out such risks as a barrier to progress, rather than as a liaison to a robust study. That attitude undermines future interactions. Establishing realistic expectations is one way to mitigate this issue.

Researchers might also offer to provide training in work that is already under way. For example, Flint has a crime-reduction programme in which residents proactively assess whether street lights are working and maintain vacant properties. Proposals that disregard what is already in place are wasteful and cause resentment. At one point, a team of researchers approached us to implement a healthy-eating project, not realizing that the Flint community had helped to develop the recipe book on which it was based. The Healthy Flint Research Coordinating Center now maintains an index of projects to discourage redundant work (one of R.C.S.'s tasks).

Before and especially during the water crisis, a string of 'helicopter researchers' from outside Flint came to study topics from environmental issues to violence. Community members were asked to fill out surveys, or learnt through informal chatter about researchers who wanted records about emergency hospitalizations.



A medical assistant checks for the presence of lead in blood samples as part of a community campaign in Flint, Michigan.

JIM WEST/ALAMY



A local church in Flint was set up as a water distribution centre because lead contamination had made the public supply unsafe.

But data and insights were not brought back to the community. Many residents felt used and dismissed. The coordinating centre now works with researchers so their results can be applied to inform and improve the community where data were collected.

Interactions are generative: when academic researchers dismiss community ideas, take them without credit, bristle at valid input, 'introduce' programmes that are already in progress or focus more on producing papers than on helping communities, residents will expect the same of other researchers. Even those with the best of intentions can be rebuffed or face distrust, something R.C.S. was attuned to when he began his transition from Flint community member to academic.

Nurture relationships

Ideally, interactions become constructive feedback loops. In 2018, E.Y.L. provided health-plan data to R.C.S.. The resulting analysis using a geographic information system (GIS) showed, for the first time, that the centre of Flint was an asthma hotspot (see 'Asthma hotspots in Flint'). This pattern correlates with historical sites of car factories and lead contamination in the soil (M. A. S. Laidlaw *et al.* *Int. J. Environ. Res. Public Health* **13**, 358; 2016). R.C.S. explored how best to show those patterns in ways that would be interpretable and helpful to community members. These results have informed targeted outreach activities, such as developing tailored materials based

on local landmarks and identifying specific neighbourhoods, churches or community groups where the materials can be distributed.

None of this would have happened without the partnership and trust we had built. The university needed access to health-plan data. Health-plan officials had to trust researchers to answer relevant questions, honour patient confidentiality and provide insight to accomplish the plan's goal.

As the value of such analysis became clear, community members were eager for more. Most neighbourhood and community groups come together to solve a specific, immediate problem, not to form a self-sustaining, long-lasting organization, so they rarely consider mechanisms for collecting long-term data. Flint now sees community members approaching researchers; they seek to evaluate programmes that they've put into place. They want data to support the fact that they do good work and to show which efforts are most effective. A true partnership has been achieved.

The partnership represents many works in progress, far beyond what we describe here. There are still conflicts, miscommunication and lost opportunities. But we now know how to set ourselves up for success as projects emerge.

The most important ingredient in making collaborations work is commitment: to producing research that is relevant, and to understanding many angles and perspectives. This means spending less time and attention on conventional metrics, such as published

papers, journal impact factors and procured grants, and much more on nurturing relationships. In true community-based partnerships, a paper is incomplete without a link back to the local community.

Although our experiences are specific to Flint, community-academic partnerships that focus on research that is relevant to policy are essential worldwide. Regions in the Rust Belt of North America, Eastern Europe and east Asia have all experienced population decline and economic problems. More will soon do so. Exploring solutions is of benefit both to researchers and to communities when they work together.

The authors

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