A RAPID-CYCLE ASSESSMENT STRATEGY FOR UNDERSTANDING THE OPIOID EPIDEMIC IN LOCAL COMMUNITIES

It is essential to involve communities in any efforts to better identify and understand the issues that they face and in the development of grass-root strategies of their own. These strategies should be informed by the lived experiences of people who use substances, people in recovery, those who have lost loved ones, community leaders, law enforcement, health/social services and substance use disorder providers.

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conducted by the **Allegheny County Health Department** in conjunction with the **Magee Women's Research Institute**, and the **Hillman Foundation**

A rapid-cycle assessment strategy for understanding the Opioid epidemic in local communities

What was the study?

The Community Opioid Project focused on eight Allegheny County opioid overdose 'hotspot' communities and took an in-depth look at what people in these communities think about what is happening with respect to opioids in the communities and what is needed to help deal with the opioid crisis.

A rapid-cycle assessment approach was undertaken to expediently identify actionable areas and factors for which interventions can be quickly developed, deployed, and assessed to begin to curb the extent and impact of this health crisis.

A leadership team (consisting of representatives from ACHD, ACDHS, CONNECT, EMS, City Government, and Pitt/Magee) selected communities for inclusion in the study and provided initial community contacts. Communities were selected based on numbers of opioid overdose deaths, geographic representation in Allegheny County, and demographic diversity. The leadership team met monthly to discuss interim findings and provide ongoing feedback on findings.

Key Findings:

- **Participants in all study communities perceived their communities as changing for the worse.**
- **Knowledge of community efforts to deal with opioid overdose was not high.**
- **Community action and accountability for crisis is impacted by: visibility of drug use and drug users; publicity and media coverage; competing concerns (budgetary, violence); stigma; perception that this is not a new problem.**
- **Perceptions of what is needed to deal with the opioid crisis most often included: access to treatment; education (for prevention, stigma reduction, and better healthcare); harm reduction; and the need for a wider family/community focus.**
- **MAT can be lifesaving, but there is mistrust about the motives surrounding its provision, and abstinence-only counter-narratives that challenge its use.**
- **Participants who had used or were currently using opioids often misused opioids as a way of self-medicating physical or psychological pain; and opioids were not the only substances they used.**

Perceptions of communities

Overall **participants perceived their communities as changing for the worse,** which was illustrated by references to infrastructure, poverty, crime, drugs, violence and transient populations. Participants generally felt that the opioid epidemic was not unique to their community.

> "I'm not sure there is anything that is unique. These problems are heightened by issues of poverty, and there is a concentration of poverty here."

Nonetheless, community members highlighted the hopefulness and resilience of people in their communities, as well as certain institutions that were serving their communities well.

In general, **knowledge of community efforts to deal with opioid overdose was not high**—which also reflects differences in community responses. If participants were aware of any community efforts to deal with the opioid crisis, provision of naloxone and community awareness efforts were most often cited. Some also mentioned law enforcement efforts, the expansion of MAT (usually buprenorphine) in their communities, and efforts to expand housing for those in recovery.

Community Differences Make a Difference

The opioid crisis cannot be viewed as separate from other socioeconomic and cultural contexts in these communities. There are major differences between communities in terms of their awareness of, attention to, and ownership of the problem of opioids, as well as in infrastructure and geography.

Factors that Impact Community Action and Accountability

- **Visibility of the problem**.
  - Our study communities differed in terms of how visible drug use and drug users were in the community.
  - While overdose numbers may be high, if the problem is hidden in private places it can remain under the radar. Are substance users visible in the community? Are people finding syringes and stamp bag litter? Where are overdoses happening?

- **Publicity and Media Coverage** of the problem in a particular community. Two study communities' issues with opioids were publicized by the media. Citizen reaction to the pieces was mixed, with anger about communities being stigmatized for their problems; at the same time the pieces served to 'wake up' the community about what was happening. Publicity of the problem had a huge impact on interventions in these communities, but communities also need to be able to **control the narrative**: follow up stories about what is being done to solve the

problems; publicity of positives in the communities. If these communities had not already had strong community leaders who were willing and able to address the opioid crisis, it is uncertain how this kind of publicity would have played out.

- **Competing concerns** in a community. Several of our study communities are facing severe budget problems, violence and/or political changes that have drawn the attention and energies of community members and leaders, thus taking the focus from opioid overdoses.

> "I mean [opioid overdose] is on our radar, but when you have pressing things where there's increases of gun violence, and that's really what I can put my finger on that's truly affecting the community, that's where the focus tends to go."

- **Stigma**—relegating the opioid overdose problem in a community to something that is happening to 'other people'--people coming in from outside (either newcomers to a community or to people passing through and using drugs in the community.)

> "Mostly the only problems we have are from the people outside."

- **Community does not 'fit' media accounts of where and to whom the overdose crisis is happening**. Overdose crisis is perceived by some as a "white river town" problem, and their communities do not fit that description.

- Perception that this is **not a new problem**. Drug use and misuse in the community become 'normalized' over decades, such the opioid overdose crisis is just a different drug that happens to be deadlier with the addition of Fentanyl.

> "For many of these people that are in the thick of this generational poverty this was never a choice and they're surrounded by other people who are in the same trenches of despair…Almost everyone knows someone who's died. And that's not scary in a way to them."

Differences in resources and relationships that make a difference in how to intervene:

- **Goods and services** Where are resources such as county offices, primary care, OUD treatment, stores located?
- **Relationships with surrounding communities**. How are neighboring communities perceived? Do they depend on each other for the provision of goods and services?

- **Geographic features** that affect movement between neighboring communities? 'People don't like to cross bridges.'
- Lack of **public transportation** between communities. "This little island…"
- Is the community **centralized or dispersed**? How large is the community geographically? Car dependent?
- **Existing organizations** already present in the community to potentially take on the issue of opioids.

These kinds of differences between communities informed our understandings of barriers to interventions. Lack of transportation to treatment and services was the most widely mentioned barrier to treatment and intervention.

What is needed?

We asked participants **what is needed to deal with the opioid crisis** in their community. Most often, participants focused on access to treatment; education (for prevention, stigma reduction, and better healthcare); harm reduction; and the need for a wider family/community focus.

Access to treatment

Participants mentioned the lack of treatment capacity overall, the lack of treatment options in communities, the difficulty of navigating the treatment landscape, and the importance of keeping people safe while they await treatment.

> "Not enough treatment beds. There is not always enough funding. There is usually a gap between when somebody demonstrates the willingness and ability to get to the bed."

> "We need more providers that are willing to prescribe Buprenorphine and do medication assisted treatment."

> "Some places that is a buffer-some kind of supportive shelter where someone can go for 5-7 days until their bed is available."

Participants who sought treatment did not do it on their own, and most information about treatment options is word-of-mouth. This means that the treatment path and modality are guided by those helping in the process.

> "A lot of people don't even know where to start [in getting treatment]. I think we need almost like a map that says, 'this is where you need to go'."

Education for prevention, stigma reduction and better healthcare

Participants in all stakeholder categories spoke about the need for education about drugs and drug addiction as part of **prevention** efforts. Many suggested that education begin earlier than high school, if not earlier than middle school. This is consistent with our findings that current and past opioid users started using various substances at young ages.

The need to **reduce stigma** as part of efforts to address the opioid crisis was a key theme of many participants. Reducing stigma was described in terms of understanding addiction as a disease, and of humanizing people who use opioids.

> "I still think **there is a huge lack of education and understanding of what addiction is and what the opioid crisis is not only in the community but in many facets like law enforcement, emergency workers, people in school.**"

> "When I started there, one of my clients said, '**Thank you. You talked to me like a human being.' I will carry that with me**."

Providers noted the lack of formal instruction that they receive about addiction and treating those with addiction. They also noted that provider stigma affects healthcare.

> "Um, I think there is a lot of fear and shame and stigma around this patient population … I mean they are like a porcupine to be around when they are in active addiction. So when a porcupine comes into your emergency room, you are like, 'Hey can somebody get the porcupine out of here? He is hurting everybody, right.'
>
> Just acknowledging they are porcupines, but they are still people under all those needles that need to get help."

> "Kind of surprised it is not mandatory that you do some type of rotation or something in addiction. I think working on the stigma is for everyone that is in health care, whether you are a nurse, a tech, whatever it is, you really need to get some experience."

> **"So, also, you know I'm finding a lot of stigma in pharmacies… my patients come back, and they will say I was told that, 'We don't have that prescription here, because we don't have people like you'."**

Participants were very supportive of the role of the certified peer recovery specialist. We understand that efforts are underway at the DHS level to train additional certified

peer recovery specialists and to create mechanisms for their compensation. Participants lauded the efforts of peer support specialists and expressed a need for more of them.

> "Like these certified peer specialists, peers will do great jobs, but there is just not enough."

Wider focus on family and community

Participants indicated that the focus on opioid overdose or on opioid users is too narrow. Both attention and funding should take a broader view on how OUD and overdose are connected to wider issues in the community that have similar precursors. Many participants suggested that employment opportunities and activities for all ages may help people from becoming involved in substance use.

> **"There is not enough focus on families. And helping the entire family…This is more of a family epidemic and that is not really talked about a lot."**

Harm Reduction: Naloxone and syringe exchange

We asked all participants if they had heard about **naloxone**, what it is used for, and how they feel about making it more widely available. Most participants had heard about it and knew that it was an opioid overdose reversal drug. Many were supportive of its' use and wider availability, but there were concerns around its' use and provision.

> **"I feel good because it [naloxone] is helping someone. But then I feel bad because [the police] had probably been at that house 3 times today. So, they abuse it. So, I don't know about that answer. I just believe everybody deserves a chance. I don't think you should just let somebody die."**

> **"I didn't ask to have asthma. I didn't ask to have food allergies. I have to pay $800 for an epi pen. You want to give Narcan to these people for free?"**

Law enforcement perceptions of naloxone were characterized by the same range of opinions as those of other stakeholders. We encountered descriptions of top-down policies that changed practice and perceptions of naloxone, as well as some police leaders who were not yet supportive of police carrying naloxone. (Police in two of our study communities did not carry naloxone at the time of the study.)

> **"You would hear a lot of 'I ain't touching that.' …Everybody seems now to be, 'That is what we do. This is the norm.' We are just very stubborn. We don't like change."** [police officer on naloxone]

Knowledge of **syringe exchange** was not as broad as that of naloxone, and there were also perceptions that it encouraged drug use.

> "There was a little story in the local paper about maybe starting a needle exchange…they don't understand or get that. They aren't happy about it either. They feel that **it is still making it too easy**."

Perceptions of MAT (esp. buprenorphine)

The visibility of successes with buprenorphine treatment is challenged by abstinence-only narratives and suspicions of the 'medical system'. Perceptions of treatment with buprenorphine vary from negative perceptions of trading one addiction with another for the profit of big pharma, to positive perceptions of an individualized treatment that lasts as long as a particular patient needs. There is a need to provide scientifically-supported and accessible information about buprenorphine treatment that is in line with best practices.

Starting Opioid Use

We listened to current and former opioid users' stories of starting opioid use. Participants started opioids for various reasons from a prescription after surgery or injury, to curiosity. They often misused opioids as a way of self-medicating physical or psychological pain, usually followed by continued use of opioids to avoid sickness from withdrawal (dope sickness).

> **"It took away the pain, took away the anxiety.** You are self-medicating for the mental health. Then it becomes such a vicious cycle."

These stories of starting are consistent with treatment providers' observations about the frequency of overlap between substance use and mental health conditions. Polysubstance use was also common. Many participants indicated that they had used a variety of substances throughout their lives, and often used or were witness to substance use at a young age. Recurrence of use was often part of participants' recovery processes.

Who did we talk to?

We interviewed 130 people and attended 29 community meetings from July 2018 to May 2019. Participants were asked to choose as many stakeholder categories as applied to them, and to indicate one primary category for purposes of the study. Sixty-two participants indicated more than one stakeholder category, sometimes several.

Stakeholder category	Primary category	Additional category
Current opioid user	5	2
Past opioid user	20	8
Parent/guardian of opioid user	2	4
Spouse of opioid user	5	9
Child of opioid user	0	8
Family member of opioid user	7	26
Government official	12	4
Healthcare/social service provider	52	8
Law enforcement/legal system	4	2
School official	1	3
Community member	17	30
Other	1	1

How can this information be used?

It is essential to involve communities in any efforts to better identify and understand the issues that they face and in the development of grass-root strategies of their own. These strategies should be informed by the lived experiences of people who use substances, people in recovery, those who have lost loved ones, community leaders, law enforcement, health/social services and substance use disorder providers. This information will help to determine action steps, targets for funding, and interventions specific to the needs and desires of individual communities.

The study was conducted by the Allegheny County Health Department in conjunction with the Magee Women's Research Institute, and the Hillman Foundation. Funding for this study was provided by the Hillman Foundation.