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## REFERENCES

1. Wakefield MA, Loken B, Homik RC. Use of mass media campaigns to change health behaviour. *Lancet*. 2010;376(9748):1261–1271.
2. Bonfiglioli CM, Smith BJ, King LA, Chapman SF, Holding SJ. Choice and voice: obesity debates in television news. *Med J Aust*. 2007;187(8):442–445.
3. Crawford R. You are dangerous to your health: the ideology and politics of victim blaming. *Int J Health Serv*. 1977;7(4):663–680.
4. Goffman E. *Stigma: Notes on the Management of Spoiled Identity*. Englewood Cliffs, NJ: Prentice Hall; 1963.
5. Carter SM, Cribb A, Allegrante JP. How to think about health promotion ethics. *Public Health Rev*. 2012;34(1):1–24.
6. Chapman S. For debate: the means/ends problem in health promotion. *Med J Aust*. 1988;149(5):256–260.

# “He Is the Object of Information”: The Intersection of Big Data and the Opioid Crisis

 See also Dodson et al., p. 1191.

Electronic systems for documenting health care delivery have accumulated vast troves of data over the past decade, including structured and unstructured information in health records from hospitals and emergency medical services. When repurposed for surveillance and epidemiology, these data have provided irrefutable gains in knowledge and helped many careers. Combined with powerful computing environments, “big data” have become central to public health surveillance.

Overdose deaths in North America also grew during the past decade, revealing intertwined epidemics involving opioid analgesics and other illicitly manufactured opioids. It is therefore not surprising to see many efforts at the intersection of big data and the opioid crisis, among them that of Dodson et al. (p. 1191) in this issue, who used patient care records from pre-hospital emergency medical services to identify neighborhoods with high overdoses in Pittsburgh, Pennsylvania. Their succinct methods show attention to detail (e.g., using road distances and travel times, manual review of cases) and consideration for privacy (e.g.,

geomasking). They found that most pharmacies were not located in neighborhoods with hotspots; those that were did not stock the opioid overdose antidote naloxone, which can be used by lay bystanders to revive victims without interaction with the formal medical system. They concluded that more pharmacies should stock naloxone in hotspot areas.

## CONTRIBUTIONS FROM PEOPLE WHO USE DRUGS

Every study, especially those using large administrative data sets, could benefit from including people with lived experience in study design, conduct, and reporting. What could people in Pittsburgh who use drugs have contributed to this analysis? More generally, what types of suggestions can people with lived experience make to improve the research enterprise?

The first kind of enhancement comes from participants being able to provide insight into practical factors that lead to intervention utilization. Perhaps there is reticence to purchase

naloxone in one’s own neighborhood, akin to “condom embarrassment.”<sup>1</sup> Perhaps the experience of buying syringes alerted customers to which stores had compassionate versus judgmental pharmacists.<sup>2</sup> Perhaps some would be afraid to ask for naloxone in a pharmacy where they buy syringes for fear of losing access to sterile injecting equipment, by unmasking a carefully cultivated (albeit fabricated) representation of why they need syringes.

Second, people with lived experience can make suggestions for additional data sources that bring applied validity to studies. Often these additional data elements can be readily obtained electronically—the low-hanging fruit of content scraping. For example, pharmacy window operation hours, drive-through pickup or delivery, and public transportation routes may have real-world ramifications of whether someone

will go to the pharmacy for naloxone.

Study participants often interact with researchers and service providers who may be unknown to new analysts. Another kind of contribution that people with lived experience can make is to provide referrals to other researchers who might contribute substantially to the analysis in question. In Pittsburgh, the public service organization Prevention Point<sup>3</sup> distributed 314 doses of naloxone per month in 2017, with an average of 53 reversals reported each month (naloxone data from Prevention Point Pittsburgh, personal communication, Alice Bell, May 18, 2018). Comparing the Prevention Point numbers with the 70 emergency medical services records per month in the Dodson et al. study shows that a substantial portion of naloxone use happens outside formal medical systems. Prevention Point clients also reported getting naloxone elsewhere, but not pharmacies. The Allegheny County Jail distributed 160 naloxone doses monthly in 2016, and a drug treatment provider distributed 222 naloxone doses monthly (naloxone data from Prevention Point Pittsburgh, personal communication, Alice

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Bell, May 18, 2018). Perhaps if Dodson et al. had combined data sources it would have helped refine recommendations for subpopulations that would benefit from pharmacy access.

People who use drugs might have particular insight into factors that affect analytic integrity. For the study of Dodson et al., naloxone-distributing organizations may have been able to quantify how likely people are to call 911 for overdose instead of their assumption that it was common practice.

## BROADER RESEARCH CONTEXT

The prescient social observer Michel Foucault summarized the position of being under surveillance: “He is seen, but he does not see; he is the object of information, never a subject in communication.”<sup>4(p200)</sup> A half-century later, the practice of big data analytics continues in this tradition; ironically, their practice is executed in object-oriented programming languages. Through four types of contributions (practical insight, additional data, networking, and analytic integrity), data scientists can find common ground with people whose experiences are represented in pixels.

Yet, to dwell solely on what people with lived experience can provide to researchers perpetuates the divide between “us” and “them.” Other models have been successful, such as the one in which people who use drugs and people with pain have actively participated by articulating what research would be meaningful to their lives and

have participated in studies.<sup>5,6</sup> The Patient-Centered Outcomes Research Institute model has been a grand experiment in patient participation. Community-based participatory research remains a useful legacy model for localized studies, but analysis of large administrative data sets is a new paradigm in which the representative participation of individuals may be divorced from a physical community. For some research questions, including those in abstinent “recovery” might be sufficient, but most studies focus on people who continue to use drugs, and they are the ones who should be included.

## HISTORICAL PERSPECTIVE

The checkered legacy of psychedelic self-experimentation in the Harvard Psilocybin Project of the 1960s, which scandalized the academic establishment by disregarding the sanctified divide between researcher and participant, has led to a vacuum of representative participation in substance use research. In the absence of alternative participation models, a common argument against including people who use drugs is the standard adopted by many institutional review boards: an intoxicated person cannot give consent to participate in research. This should not be confused with engaging people who use drugs in study design, conduct, and reporting.

Reflexive arguments for why drug users should not be engaged come easily because we work in an environment

structured to make us equate people who use drugs with people who need our help. Beyond stigma, the practicalities remain: building trust between research teams and drug user advocates takes time, most training curricula do not provide instruction on how to effectively do so, and efforts are not supported by funders. Knowledge gleaned from participatory epidemiology is more insightful, and diversity of experience can produce groundbreaking results. But perhaps there is also a grander sense of duty. As early as 1505 CE, the constitution of Poland enshrined the Latin phrase *Nihil de nobis, sine nobis*, “Nothing about us without us,” to declare the right of direct participation in policy decisions of people affected by those policies.

In closing, I admit I feel a pang of guilt when I cite national survey data enumerating millions of nonmedical users of prescription drugs but have not invited a single one of them to be part of my research team. Although well intentioned, I have failed often, but I have also found collegial connection and more impactful science when I have made the effort to include directly affected people. How can we hold ourselves accountable? One thought is to voluntarily include in journal ethics statements the level of participation by directly affected people. If none were engaged in the study, then a brief explanation of why their exclusion does not bias the findings could be provided. This is consistent with suggestions to include directly affected people in scientific conferences.<sup>7</sup> Perhaps a public moment of self-reflection will bring us empathy and reveal

a path toward the meaningful engagement of people with lived experience. *AJPH*

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## REFERENCES

- Moore SG, Dahl DW, Gorn GJ, Weinberg CB, Park J, Jiang Y. Condom embarrassment: coping and consequences for condom use in three countries. *AIDS Care*. 2008;20(5):553–559.
- Paquette CE, Syvertsen JL, Pollini RA. Stigma at every turn: health services experiences among people who inject drugs. *Int J Drug Policy*. 2018;57:104–110.
- Bennett AS, Bell A, Doe-Simkins M, Elliott L, Pouget E, Davis C. From peers to lay bystanders: findings from a decade of naloxone distribution in Pittsburgh, PA. *J Psychoactive Drugs*. 2018;9:1–7.
- Foucault M. *Discipline & Punish: The Birth of the Prison*. Trans. A Sheridan. New York, NY: Vintage Books; 1995.
- Larance B, Dobbins T, Peacock A, et al. The effect of a potentially tamper-resistant oxycodone formulation on opioid use and harm: main findings of the National Opioid Medications Abuse Deterrence (NOMAD) study. *Lancet Psychiatry*. 2018; 5(2):155–166.
- Hayashi K, Fairbairn N, Suwannawong P, Kaplan K, Wood E, Kerr T. Collective empowerment while creating knowledge: a description of a community-based participatory research project with drug users in Bangkok, Thailand. *Subst Use Misuse*. 2012;47(5):502–510.
- Chu LF, Utengen A, Kadry B, et al. “Nothing about us without us”—patient partnership in medical conferences. *BMJ*. 2016;354:i3883.