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Reducing Harm by Designing Discourse and Digital Tools for Opioid Users' Contexts: The Chicago Recovery Alliance's Community-Based Context of Use and PwrdBy's Technology-Based Context of Use

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ABSTRACT

The United States is struggling with an opioid overdose (OD) crisis. The opioid OD epidemic includes legally prescribed and illicitly acquired opioids. Regardless of if an opioid is legal, understanding users' contexts of use is essential to design effective methods for individuals to reverse opioid OD. In other words, if health information is not designed to be contextually relevant, the opioid OD health information will be unusable. To demonstrate these distinct healthcare design contexts, I extend Patient Experience Design (PXD) to include community-based and technology-based contexts of use by analyzing two case examples of the Chicago Recovery Alliance's and PwrdBy's attempts to decrease deaths by opioid OD. Next, I discuss implications of community-based and technology-based PXD within communities of opioid users, critiquing each method and suggesting four contexts of use-heuristic categories to consider when designing health communication information for users in these contexts.

CCS Concepts

• **Human-centered computing~Collaborative and social computing devices**

Keywords

opioid epidemic; health communication design; risk communication; patient experience design

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INTRODUCTION

In healthcare settings and during medical encounters, complexities exist that are specific to these particular healthcare communication contexts. For example, regarding patient discharge instructions (PDI[1]), Gouge (2017) contended that forms "register the complexity of the [healthcare] exchange of which they are a part" (p. 2). As a rationalization for the necessity of Patient Experience Design (PXD), Melonçon (2017) suggested, "current theoretical orientations do not sufficiently account for unique health and medical contexts" (p. 21). Therefore, in the "increasingly specialized nature of biomedical practice and its attendant complexity . . ." (Gouge, 2017, p. 1) and the "changing nature of healthcare" (St. Amant, 2017a, p. 63), new methods are required to meet users' needs in healthcare communication contexts. Specifically, within the exigent opioid crisis and its social, emotional, and legal complexities, these new methods must respond to users' (in all senses of the word) unique healthcare contexts of use.

Unquestionably, the United States is struggling with an opioid crisis. Consequently, the Centers for Disease Control and Prevention (CDC, 2017b) reported "overdoses from prescription opioids [e.g., oxycodone, hydrocodone, and methadone] are a driving factor in . . . the increase in opioid overdose deaths," claiming deaths from prescription opioid overdose (OD) have more than quadrupled since 1999 (para. 2). The CDC declared that 91 people die of opioid OD every day across the United States (para. 1). The selection of opioids[2] has expanded from heroin and morphine to include, for example, Oxycontin, Percocet, Dilaudid, Vicodin, methadone, codeine, Norco, fentanyl, and tramadol (American Addiction Centers, 2018). In fact, the current opioid epidemic includes illicit street drugs like heroin and fentanyl, as well as prescribed drugs like Oxycontin and Vicodin. Now more than ever, more opioids are available for use either medicinally or recreationally, which increases the risk of addiction and opioid OD. In instances of legally prescribed opioid ingestion, users might not realize a danger of OD. For illicit opioids, users might avoid emergency services in OD situations for fear of legal ramifications. Regardless, the CDC (2017b) has declared a list of preventative

measures to reduce harm, including "[expanding] access and use of naloxone—a safe antidote to reverse opioid overdose" (para. 4). For both contexts, regardless of an opioid's legality, designers need to understand users' contexts of use to design effective methods for individuals to reverse opioid OD. In other words, if health information is not designed to be contextually relevant, the opioid OD health information is unusable. As such, the guiding question for this entry asks, "Outside of public health, what efforts are being taken to reduce harm from opioid OD?"

Arduser (2017) explored patient agency and expertise in managing chronic diabetes care outside of clinical settings. Similarly, the Chicago Recovery Alliance (CRA)—a community-based not-for-profit organization—relies on lay expertise within communities of opioid users to prevent and to reverse OD[3]: a novel community-based approach to reduce opioid OD deaths. The CRA provides users with legally prescribed naloxone to temporarily reverse opioid OD within a community-based context of use. In contrast, the Food and Drug Administration (FDA) used a smartphone application (app) competition with technology-based crowdsourcing as a strategy to educate users and thus to reduce harm from opioid use. Team PwrdBy's prototype app, OD Help, uses a technology-based approach to crowdsource help for opioid users and naloxone delivery. Crowdsourcing relies on communities of users to engage with problems so as to solve them collectively (Brabham, Ribisl, Kirchner, & Bernhardt, 2014, p. 179). The two (CRA's community-based and FDA's technology-based) approaches provide two communication design strategies to reduce harm by engaging users outside the official public health channels to reverse increasing upticks of opioid OD. In both cases, the CRA and FDA depended on users in two distinct regards and in two specific healthcare contexts of use. These two approaches highlight two unique contexts of use in PXD (Melonçon, 2017): community-based and technology-based approaches.

To demonstrate these distinct healthcare design contexts and to situate my argument, first, I provide a reading of community-based and technology-based contexts of use to reduce harm from opioid OD—to support the use of PXD and to assist efforts in risk communication. Second, I introduce readers to naloxone, a drug developed to reverse opioid intoxication and temporarily stop OD. Third, I present two cases: the CRA's and PwrdBy's attempts to decrease deaths by opioid OD. And finally, I discuss implications of community-based and technology-based PXD within communities of opioid users, critiquing each method and suggesting four context-of-use heuristic categories to consider when designing health communication information for users.

PATIENT EXPERIENCE DESIGN (PXD): CONTEXTS OF USE

Expanding notions of audience and user experience (UX), Melonçon (2017) advocated to extend UX to include PXD. PXD is a "patient-focused design [practice] that [mirrors] the experiences of patients" (p. 19). Specific to healthcare contexts, Melonçon defined PXD as "a participatory methodological approach centered on contextual inquiry to understand the relationship between information (or technology) and human activities in healthcare" (p. 20). A workplace methodology, contextual inquiry uses interviews and observation as the primary data-collection methods and textual-artifact analyses to complement the former two methods. In other words, Melonçon advocated for contextually-based methods to inform the design of health materials for patient users. In this way, PXD theoretically and directly responds to the distinct contexts of use to design communication and materials. Melonçon's conceptualization of PXD and contexts of use are particularly integral regarding the opioid OD epidemic. Knowledge about opioids, legal repercussions, and opioid illicitness might contextually factor into any user's decision-making process when asking for help in instances of opioid OD, meaning the contexts and realities in which these users make decisions are integral elements to consider when designing health information for these situations.

Furthermore, recognizing and designing for "the world around the object of study" (Simmons & Zoetewey, 2012, p. 9) as well as refining PXD for international contexts, St. Amant (2017a) offered international PXD (I-PXD) to reflect the particularities of geography, location, and setting. St. Amant agreed regarding PXD's necessity and suitability for healthcare contexts. Specifically, St. Amant (2017b) suggested that useable health materials' designs must mirror the contexts within which they are used. In other words, "the first step in designing materials is to understand the context or setting in which the intended audience will use them" (p. 110). Furthermore, St. Amant (2017b) pointed out,

> . . . one needs to know where the members of a particular audience will try to use a given item/perform a particular task and what other factors are expected to be present in that environment and to be used to perform that process. (p. 111)

In the opioid epidemic, and as presented in this entry's cases, the context of use requires the willing participation of users, the availability and mobility of naloxone, and the credibility of participants. Once again, without knowledge about users' contexts of use—including their material realities, designers cannot properly design health information for these life-and-death situations.

Unlike Melonçon's PXD and St. Amant's I-PXD conceptualizations, the opioid epidemic traverses the boundaries from medical and care communication to public health crisis communication. In this way, the circulation of health communication from individual, personal-care contexts to wider, public health communication contexts complicates the dissemination of information and provides opportunities to engage audiences and stakeholders in novel ways. More concretely, opioid OD derives from both legally and illicitly procured opioids. Legally prescribed opioids involve medical communication (care communication in risk contexts), yet the opioid epidemic necessitates a public health crisis communication context. In each context of use, the circumstances require different tactics to communicate with users. As such, the contexts of use and the resulting communication about those contexts are dynamic and integral for effectiveness. For example, the CDC launched *Rx* [prescription] *Awareness* in September 2017 in an effort "to increase awareness and knowledge among Americans about the risks of prescription opioids and stop inappropriate use" (CDC, 2017a, para. 2). The *Rx Awareness* campaign "featur[es] real-life accounts of people recovering from opioid use disorder and people who have lost loved ones to prescription opioid overdose" (para. 2). *Rx Awareness*'s context of use is public health and crisis risk communication, which extends beyond the scope of a solitary medical or healthcare encounter and relies on the social capital of and trust in the CDC through the personal stories of those negatively impacted by opioids. In this case, the CDC aims to engage an audience of prescription opioid users to provide risk information about ingesting these pharmaceuticals. However, prescription-

opioid users are only a portion of the population that ingests these drugs. The audience that the CDC (wisely) does not engage with *Rx Awareness* are illicit opioid users—opioid users who exist in a different communication context outside the scope of the audience addressed with *Rx Awareness*.

Communicating health information in complex, dynamic health and medical contexts is challenging and potentially problematic, especially considering the life or death stakes in the opioid OD epidemic. The opioid epidemic is an exigence and necessitates effective, factual, user-friendly communication of health information. Melonçon's (2017) PXD is reflexive to the intricacies and complexities of relaying "timely, accessible, accurate, useful, and understandable" health information to end-users (p. 24). St. Amant (2017a) noted "[usability] in health and medical communication involves designing for both the user and the context in which s/he uses items" (p. 63). In the cases I present, each entity has designed health-related information for opioid users to reverse OD with naloxone within two particular risk communication contexts.

Ding's (2018) exploration of risk communication outside an official mediascape to highlight the role of transnational whistleblowing in the severe acute respiratory syndrome (SARS) health crisis pinpointed larger societal values as an impetus for action in public health contexts. In fact, Ding concluded that whistleblowers experience ". . . value clashes [that] bring significant personal consequences and can lead to severe negative outcomes, ranging from social isolation to job loss to death" (p. 43). Similarly, the stigmatization of illicit and prescription drug use and the potential outing as drug users or abusers provides negative outcomes like those Ding identified. In other words, the health communication context presumes certain risks associated with opioid use and the discovery of that opioid use. In communication contexts such as these, the design of health information and other materials should reflect the nature of opioid uses, as well as the desires of some users to avoid "significant personal consequences [that] can lead to severe negative outcomes" in extreme communication situations (p. 43) like opioid OD. In certain instances, the negative outcomes—e.g., arrest and potential criminal conviction—might override a user's willingness to request assistance from emergency services (e.g., paramedics) regardless of the quality of health information and materials designed for opioid users or the likelihood of death by avoiding assistance from emergency service professionals.

In the cases I present, I build from the recent momentum (Melonçon, 2017; St. Amant, 2017a; St. Amant, 2017b) responsive to the specialized, complex, and dynamic healthcare contexts assumed in PXD. I explore two attempts to reduce harm from opioid use. In both instances, "by shrinking the scale of context," I evaluate the intended audience and efficacy of each approach (per Melonçon, 2017, p. 22), as examined in these contexts. By focusing on the particular contexts of an individual's lived experiences, as Melonçon and St. Amant have declared, the individual's material realities become integral factors regarding their care and the design of health-related materials for that care.

Building on Melonçon's (2017) PXD's domains of knowledge and primary concepts (see Figure 1; p. 25), I suggest the CRA and PwrdBy designs were created to save the lives of opioid users, knowing their audiences and those audiences' specific, complex healthcare contexts. In the first case, I highlight the PXD approach used by the CRA. The second case explores the FDA contest-winning PwrdBy's prototype smartphone app OD Help. Both approaches reflect particular opioid contexts of use and each approach reflects a particular user within that opioid context. The CRA uses a *community-based approach* context of use to prioritize the users' experiences, perceptions, and physical locations. A community-based PXD approach is participatory and derived from intimate knowledge about users and their communities. As a second example from Melonçon's PXD's conceptualization, a *technology-based approach* like that shown in the case of OD Help, prioritizes the technology that the user will use. The technology-based approach is bolder in its assumptions about the contexts of care and presumes users will have access to both the technological and pharmaceutical interventions that the approach requires. As the next sections show, unlike the community-based approach, for technology-based PXD context of use, the physical location is mutable and, as is the naloxone in these contexts, mobile.

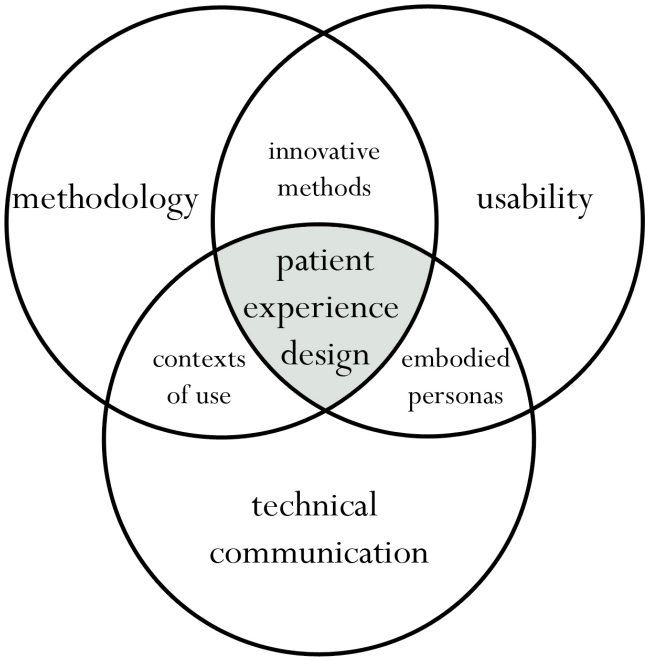

Figure 1: Melonçon's (2017) domains of knowledge for Patient Experience Design (PXD) with primary concepts.

NALOXONE AND THE LAW

Since 1971, injectable Narcan (known by the generic name naloxone hydrochloride or as naloxone since 1985) has stopped opioid OD and temporarily reversed OD (Gupta, Shah, & Ross, 2016). The National Institute on Drug Abuse (NIDA; 2016) describes naloxone as

> a medication designed to rapidly reverse opioid overdose. It is an opioid antagonist—meaning that it binds to opioid receptors and can reverse and block the effects of other opioids. It can very quickly restore normal respiration to a person whose breathing has slowed or stopped as a result of overdosing with heroin or prescription opioid pain medications. (para. 1)

Naloxone (the less expensive, generic Narcan) is not addictive and cannot cause OD itself (Maxwell, Bigg, Stanczykiewicz, & Carlberg-Racich, 2006, p. 90). NIDA explains three methods to administer naloxone: 1) as an injectable (naloxone) by experts

with professional training; 2) as an auto-injectable (Evzio) by non-experts without professional training; and 3) as a nasal spray (Narcan) by non-experts without professional training.

The FDA fast-tracked naloxone (per Gupta et al.[4] [2016] in the *New England Journal of Medicine*) as a fixed dose auto injection in 2014 for non-expert[5] users to administer. And since 2015, with FDA fast-tracked approval, the fixed dose nasal spray (Narcan) has been available for non-healthcare professional users to administer. Naloxone was used primarily for heroin overdose (80% in 2013); however, death from heroin OD was double the rate compared to prescription opioid ODs in 2013 (p. 2213). Integral to opioid users' contexts of use, laws regarding naloxone vary state by state. In specific states, only non-experts may administer the auto-injectable Evzio and nasal spray Narcan. In other states, according to NIDA (2016), naloxone may be dispensed in outpatient contexts without a physician's prescription, whereas other states legally require a physician's prescription (para. 8).

The Prescription Drug Abuse Policy System (PDAPS; 2017) is a clearinghouse for state laws regarding naloxone access for researchers and the public. According to PDAPS, all 50 states and the District of Columbia currently have naloxone access laws; however, only 37 of the 51 jurisdictions provide immunity from criminal prosecution (n.p.).

Illinois laws allow lay responders to administer naloxone. According to Naloxone Overdose Prevention Laws, since 2010, Illinois has had naloxone-access laws (20 Ill. Comp. Stat. 301/5-23), which provide professional and criminal immunity for qualified individuals prescribing or distributing naloxone hydrochloride to individuals who are not healthcare professionals. Although healthcare professionals who prescribe naloxone are granted professional immunity, they are not provided civil immunity. In Illinois, dispensing agencies are granted civil, criminal, and professional immunity, which enables the CRA to do its work in the greater Chicagoland area. Additionally, in Illinois, laypersons distributing naloxone are immune from criminal and civil liability. However, in Illinois, naloxone must be acquired legally and accompanied by a prescription. If a user possesses naloxone without a prescription, that user is charged with a criminal offense. In other words, legislature in the State of Illinois has made it possible for entities and their workers to get naloxone into users' hands (and to legally protect those who do).

COMMUNITY-BASED CONTEXT OF USE: THE CHICAGO RECOVERY ALLIANCE

Self-described as "a racially and ethnically diverse group," the CRA (n.d.) includes individuals with backgrounds in education, addiction treatment, healthcare, and law as well as those "living with HIV and drug use" (para. 1). Additionally, the CRA's uniqueness emanates from its commitment to and support of the community it serves: "individuals affected by HIV and drug use" (para. 1). With a significant increase of heroin-OD deaths in Chicago from 198 deaths in 1996 to 466 deaths in 2000 (425% increase), the CRA's "Harm Reduction Outreach Program" sought to get legally prescribed naloxone in the hands of more opioid users (Maxwell et al., 2006, p. 90). The CRA primarily aims to help audiences that include injection drug users (IDUs) but not necessarily prescription opioid users.

Since 1991, via this program, the CRA (www.anypositivechange.org) has assisted people—no matter their personal lifestyle choices—to lead safer lives. The CRA (n.d.) is an "action organization"—it "[serves], [supports], [educates], and [advocates] with others for reducing drug-related harms" (para. 1). The CRA provides free, safe, and legal needle/syringe exchanges, addiction treatment, cotton and alcohol pads, cookers,[6] water-based lubricants, male and female condoms, and healthcare referrals and assistance for IDUs. Additionally, and importantly, the CRA provides naloxone to heroin and opioid users (10 ml multidose vials of 0.4 mg/ml naloxone injections).

The CRA also uses stationary (6 storefront sites) and mobile (16 van sites) methods to interact with IDUs across Chicago's various neighborhoods as well as in directly adjacent, impacted towns (Maxwell et al., 2006, p. 90). The CRA has a "history as a widespread and trusted harm reduction program," which positioned the CRA as a likely candidate to intervene in the opioid OD death epidemic (p. 90) in Chicago. In conjunction with—and pre-dating—naloxone access laws in Illinois from 2010, physicians volunteered to prescribe and dispense naloxone with the CRA beginning in 1998 (p. 90). The CRA's harm reduction program covers

> A curriculum[7] [. . .] that includes basic opioid neurophysiology, pharmacodynamics and pharmacokinetics of commonly used opiates, pharmacology and pharmacokinetics of naloxone and other opiate antagonists, risk factors and prevention techniques for opiate overdose, signs and symptoms for the early recognition of opiate overdose, prevention of choking and aspiration in the unconscious patient, techniques of rescue breathing, routes of administration and dosing guidelines for naloxone, and protocols for follow-up care. All CRA outreach specialists are trained via this curriculum to engage and inform participants regarding naloxone and its availability through CRA. (p. 90)

After sharing the curriculum and recording a medical history from IDUs, users are legally dispensed naloxone in a 10 milliliter (ml) multi-dose vial. Additionally, IDUs are provided with sterile intramuscular syringes; pocket guide instructions for OD awareness and treatment; and documentation verifying an IDU's possession of naloxone is legal, medically warranted, and physician ordered. After an IDU receives naloxone, a volunteer physician signs a medical order to verify the medical directives for naloxone and the medical order is placed in the participant's chart as part of the IDU's official medical record with CRA (p. 90).

The main Webpage for the CRA provides an embedded video about how to administer naloxone. The thumbnail for the video reads, "HIT 'EM IN THE ARM, THIGH, OR ASS." By "hit 'em," the CRA means to inject the IDU with a life-saving dose of naloxone via intramuscular injection. The CRA video is divided into six "chapters" or sections and is a little more than 13 minutes in duration. Preceding the video content is a warning: "Viewer Advisory: This video contains graphic images of drug use and scenes from an actual drug overdose" (CRA, 2010). The video contains real-life coverage of Steve Kamenicky, who really overdosed and was unresponsive during filming, but the other OD scenes in the video are scripted. The first three chapters are devoted to

1. identifying the signs of opioid OD ("blue lips," "not breathing right," "won't wake up," and "won't react

to pain");

2. taking action ("call 911," "roll onto side," "clean out mouth," "roll onto back," "tilt head up," "pinch nose," "give two quick breaths," and "give one big breath every 7 seconds"; and

3. using "Narcan" or naloxone ("pop the top," "un-wrap a muscle syringe," "make sure point is tight," "put needle in bottle of Narcan," "draw 1 cc [cubic centimeter] into the syringe," "and "hit 'em with Narcan in the upper arm, in the thigh, or in the ass" (CRA, 2010).

Since 2001,[8] according to Maxwell et al., (2006), the CRA's harm reduction program has provided "more than 3,500 10 ml (0.4 mg/ml) [legally prescribed] vials of naloxone" (p. 89). Although correlation is not causation, they reported, "a consistent trend of increasing heroin overdose deaths, from 198 in 1996 to 466 in 2000, was reversed in 2001, the year that [CRA] instituted this program, with 374 deaths in 2001, 344 in 2002, and 324 in 2003" (p. 91). CRA Director Dan Bigg reported, "We have our choice of one Evzio (so-called auto injector), 23 nasal sprays [Narcan], or 103 kits of injectable naloxone. Each saves a life in case of opioid-related OD. Guess which is the only one we use?" (D. Bigg, personal communication, September 17, 2016). In other words, of the three methods to "[save] a life in case of opioid-related OD," the CRA chooses to use the multi-dose vial of injectable naloxone to reverse opioid OD.

The CRA's curriculum, naloxone supplies, and lay expertise applied as peer reversals rely on their state-supported naloxone access laws and community-based approach to save those who otherwise might die from opioid OD. Peer reversal, or the idea that life-saving naloxone should be available by prescription to IDUs to use this treatment—without a physician or healthcare professional—"in the field" is integral to the harm reduction program (Maxwell et al., 2006, p. 90). Based on the curriculum, the CRA continues to turn inexpert IDUs into experts who can administer life-saving naloxone in instances of heroin or other opioid ODs. Peer reversals, which rely on lay expertise, temporarily reversed opioid OD in 319 instances (p. 91). According to its annual report, the CRA (2017) has cumulatively (from inception through 2016) received reports of more than 10,970 peer reversals of opioid OD (p. 1). Additionally, according to the CRA Annual Report, the curriculum has been taught to 72,610 people. Each individual has also been given a naloxone kit and access to the training video to share with others (p. 1).

TECHNOLOGY-BASED CONTEXT OF USE: PWRDBY'S OD HELP

Strategically, to combat opioid OD, federal agencies (Substance Abuse and Mental Health Administration, Department of Health and Human Services, and the CDC) have sought to expand access to and use of naloxone. The FDA has promoted the nasal spray method, striving to fast-track the over-the-counter (OTC) availability of the nasal spray naloxone (Narcan). The user-friendly material design of naloxone and the FDA's support in making the product available OTC prompted the FDA to hold a competition to crowdsource a naloxone app to connect opioid users with pharmacies and individuals who carry naloxone spray (or naloxone carriers). The competition took place in October 2016. The FDA (2016a) described the FDA Naloxone App Competition (#naloxoneapp) as

> encourag[ing] computer programmers, public health advocates, clinical researchers, entrepreneurs and innovators from all disciplines to develop creative strategies to combat the rising epidemic of opioid overdose.
>
> Specifically, the goal of this Competition [was] to spur innovation around the development of a low-cost, scalable, crowd-sourced mobile phone application that helps increase the likelihood that opioid users, their immediate personal networks, and first responders are able to identify and react to an overdose by administering naloxone, a medication that reverses the effects of opioid overdose. (paras. 1–2)

In total, 45 apps were submitted for the competition. The winning team—Team PwrdBy—created an introductory video (PwrdBy, 2016) to explain its naloxone phone app, OD Help.[9] OD Help was described as

> . . . a simple, easy-to-use mobile app designed to connect potential opioid overdose victims with a crowd-sourced network of naloxone carriers. OD Help can easily be tailored for use in rural or urban areas by expanding or contracting the radius within which naloxone carriers are sought. An additional innovative feature of OD Help is the optional interface with a breathing monitor to detect when a victim's breathing rate is dangerously low, a sign of an opioid overdose. Hence, if the victim is alone and unable to call for help, OD Help will detect the diminished breathing and alert a naloxone carrier of the potential overdose. Other features of OD Help include: only alerting people in one's support network and allowing naloxone carriers to disable alerts when they are unable to respond. The app also provides instructions on how to correctly diagnose an overdose and administer naloxone and helps contact emergency medical services when help is required. (FDA, 2016b, para. 2)

Similar to other healthcare apps that rely on crowdsourced help—like My Eyes, for visually impaired individuals, and PulsePoint, which connects off-duty health professionals and others trained to administer Cardiopulmonary Resuscitation (CPR)—OD Help is described as "a mobile application designed to connect potential opioid overdose victims with a crowd-sourced network of naloxone carriers" (para. 2). OD Help was designed to provide timely access to naloxone and to detect OD. Importantly, the app has two specific users: opioid users and naloxone carriers. As designed in the prototype, when users download the app, they register as either an opioid user or a naloxone carrier. (Figure 2 shows OD Help's prototype interface for opioid users, and Figure 3 shows OD Help's prototype interface for naloxone carriers.)

In the explanatory video for OD Help, the product lead, Chris Rovin, explained that the healthcare app tackles two problems: providing timely access to naloxone and detecting OD when individuals are alone. To facilitate "timely interventions," PwrdBy engaged Uber, Lyft, and Rover.com to use "existing, on-demand crowd-sourced networks" to deliver naloxone to opioid users (PwrdBy, 2016). OD Help also provides users opportunities to pre-load contacts to create a personalized network of helpers within OD Help (PwrdBy, 2016). To show how OD Help works to provide solutions to these two problems, the video includes two hypothetical OD scenarios.

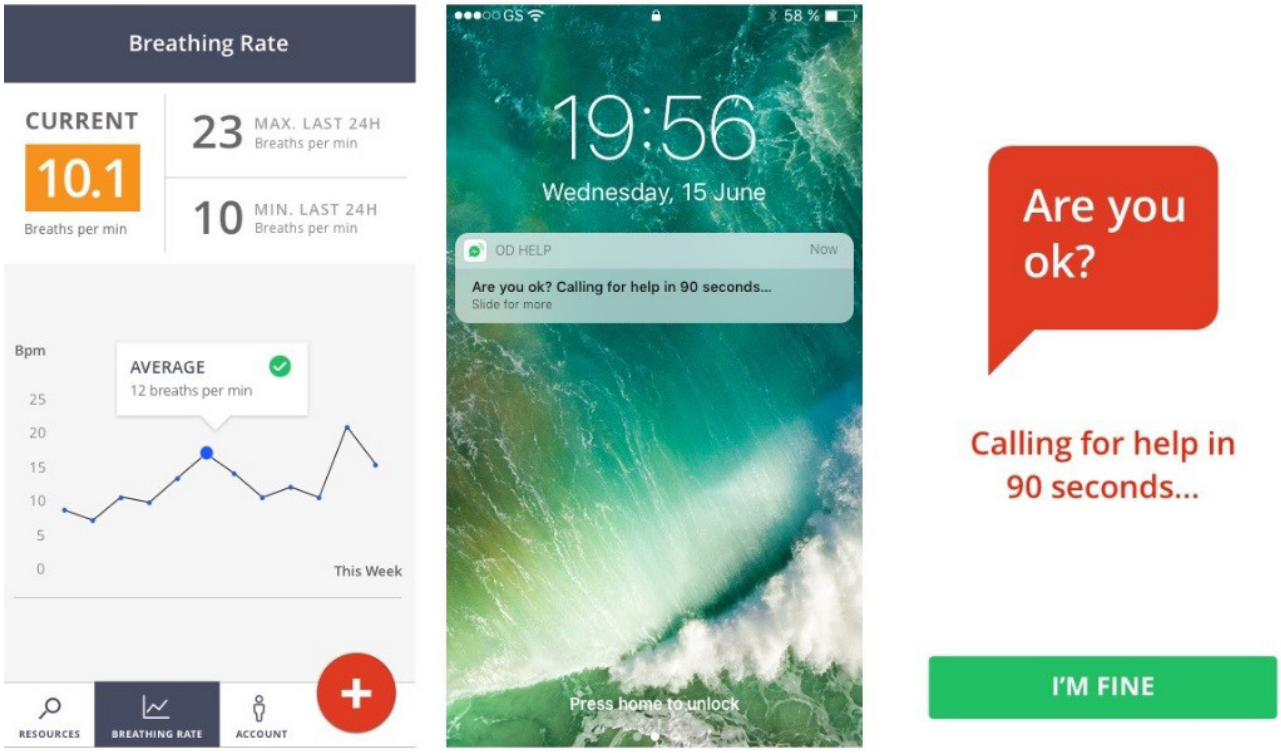

Figure 2: OD Help (PwrdBy, 2018) prototype screenshots for opioid users.

Once registered and logged in (see Figure 2 top left and top center), a user can use OD Help.

In the first scenario, a man overdoses on heroin. He is with a friend who then uses the app to alert the naloxone carrier network, including local paramedics, to request naloxone nasal spray. In the scene, the naloxone is brought by an Uber driver and administered through a nasal passage by the friend, and the individual's OD is reversed. In the second scenario, a woman who has taken Vicodin is alone at home. She is connected to Spire—a breathing monitor (Spire, n.d.)—through her smartphone (see Figure 2 right), which is integrated with OD Help. When her respirations decrease to fewer than six breaths per minute, OD Help vibrates through her smartphone. Because the user had not turned off the alarm (see Figure 2 right), members of her pre-loaded personalized network were alerted. At the end of the scene, a friend appears next to the woman's bedside with naloxone nasal spray. In both scenarios, if a user regains consciousness while a request for naloxone nasal spray through OD Help has been made, the request can be canceled (see Figure 2). We can assume that OD Help's healthcare context includes both IDUs and opioid pill users based on these two hypothetical scenarios.

Users can register as an opioid user or a naloxone carrier. As is shown in Figure 3, once an opioid user has requested naloxone, naloxone carriers—like the one in the second hypothetical scenario—are alerted, and the naloxone carrier responds if he or she can or cannot help (Figure 3 top center). Drawing on existing mapping technologies, naloxone carriers can see the distance from their location to the person who has requested the naloxone once naloxone has been requested (Figure 3 top right). If users respond affirmatively that they can deliver the naloxone, then OD Help shows walking and driving times to the destination (Figure 3 bottom left) and the related map for walking or driving directions (Figure 3 bottom center). Once the naloxone has been delivered, the naloxone carrier selects "Naloxone Delivered" (Figure 3 bottom right).

The personalized network option from OD Help utilizes a similar reliance as the CRA on lay expertise for the peer reversals by non-experts; however, the help is crowdsourced through existing networks and operationalized via the app. Both OD Help and the CRA recognize the innate importance of naloxone's availability outside traditional healthcare contexts (i.e., emergency departments, pharmacies, and physician's offices) and "in the field." The CRA's curriculum provides IDUs naloxone within a context to educate users and leverages community-based knowledge. OD Help relies on technology-based approaches to reach users and address the problems PwrdBy identified: timely access to naloxone and detection of OD when a user is alone.

REDUCING HARM IN COMMUNITY-BASED AND TECHNOLOGY-BASED HEALTHCARE CONTEXTS OF USE

Nearly 50 years ago, Gore Vidal's essay "Drugs" appeared in *The New York Times*. In it, Vidal (1971) argued,

> It is possible to stop most drug addiction in the United States within a very short time. *Simply make all drugs available and sell them at cost* [emphasis added]. Label each drug with a precise description of what effect—good and bad—the drug will have on whoever takes it. This will require heroic honesty. Don't say that marijuana is addictive or dangerous when it is neither, as millions of people know—unlike "speed," which kills most unpleasantly, or heroin, which is addictive and difficult to kick. (para. 1)

Unfortunately, Vidal's pronouncement from one-half of a

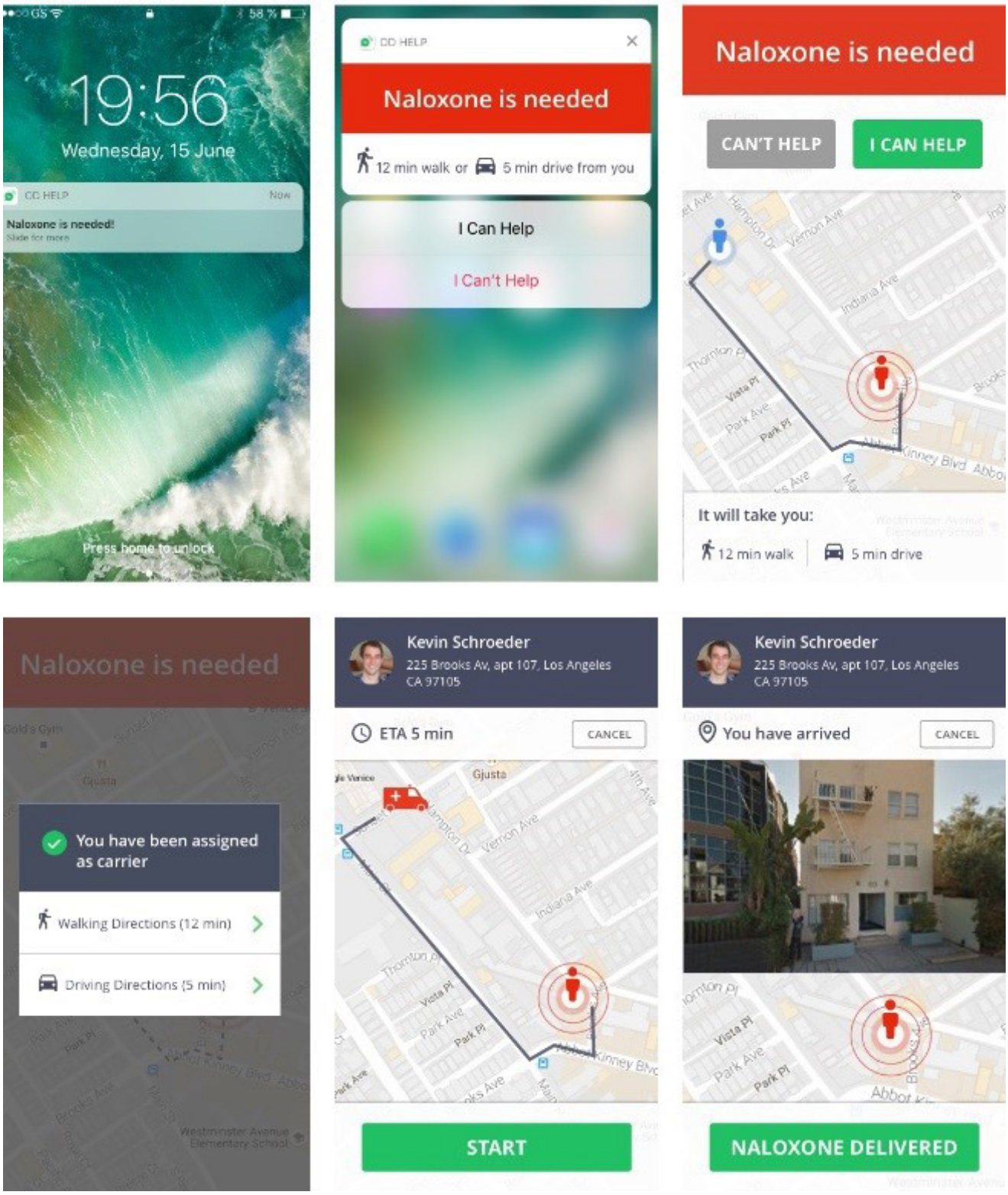

Figure 3: OD Help (PwrdBy, 2018) prototype screenshots for naloxone carriers.

century ago and subsequent drug education about heroin has not deterred individuals from using it. In fact, Vidal might be labeled wrong: labeling heroin's effects has not contributed significantly enough to reducing harm from heroin use. In healthcare settings, opioids are prescribed legally by physicians and administered to relieve pain. However, when a physician-prescribed method to acquire opioids for pain management ceases, illegal opioids like heroin are sometimes used as a substitute—a detail integral to understanding the opioid users' context of use prior to designing healthcare information in opioid OD contexts. In other words, in certain situations when individuals ingest opioids, the context is an illegal one, which suggests users are reluctant to seek OD help via

official emergency methods (i.e., paramedics and police). Society and "value clashes" position individuals to experience unwanted personal consequences and "can lead to severe negative outcomes, ranging from social isolation to job loss to death" (Ding, 2018, p. 43). The extreme SARS communication situation Ding analyzed conveys risk similar to the contexts that opioid users experience. In designing communication to reduce the skyrocketing number of deaths due to legal and illegal opioid OD, health communication designers must account for users who do not want their opioid use to be exposed, regardless of the cost, and the users' willing participation.

To reduce harm, the CRA's community-based and PwrdBy's technology-based contexts of use both depend on the willing participation of the opioid users and an available supply of naloxone. These approaches are integral to the design and deployment to reduce harm from opioid OD. In both cases, a network of lay expertise is required to reduce harm by administering naloxone in cases of opioid OD. The CRA counts on individuals, sometimes IDUs, to correctly administer naloxone to those who have ODed. As Maxwell et al. (2006) pointed out, the "[prescription] of antidotes for peer administration in emergency situations has become routine medical practice in certain situations" (p. 90). Similar dependence on lay expertise in healthcare contexts include healthcare situations involving diabetic individuals (see Arduser, 2017) and those in anaphylactic shock. Diabetics and those in anaphylactic shock rely on other individuals to administer life-saving insulin and auto-injected epinephrine. In this way, reliance on lay expertise is not novel; however, the crowdsourcing method in the opioid OD context is unique and potentially ineffective.

Brabham et al. (2014) advocate for crowdsourced methods to tackle public health exigencies, claiming "a continuum of active user participation" (p. 180). Additionally, those in the CRA community depend on the CRA for a supply of intramuscular needles and naloxone. Without IDUs reaching out for intramuscular needles and naloxone and willingly participating in the community-based approach, the CRA's harm reduction method would not work. Similarly, the fundamental concept of OD Help assumes the "willing participation of the opioid user [as] crucial for this work" (PwrdBy, 2016, n.p.). PwrdBy assumes that opioid users will voluntarily use the smartphone app and those in OD Help's trusted network of naloxone carriers will participate too—a gamble on the willingness of individuals in these networks. OD Help's method to reduce harm depends upon human factors that are assumed but not guaranteed. For example, OD Help presumes that using pre-existing crowdsourced mapping technologies (Uber, Lyft, and Rover.com) will provide timely mobility and delivery of available naloxone to users. These are risky and potentially deadly assumptions.

In both community-based and technology-based contexts of use, they require and depend on the discretionary participation of IDUs and other individuals in the networks upon which they draw to reduce harm from opioid OD. To a greater degree, these harm reduction programs trust individuals to provide, possess, and administer naloxone in time to save users' lives. For the CRA's IDUs, the trust derives from social proximity[10] and the nearness of the CRA to IDUs. For OD Help, the trust emanates from those who register as opioid users to those who register as naloxone carriers and who populate the users' personal networks. In both cases, unforeseen instances can interfere with administering naloxone. For example, if two opioid IDUs simultaneously OD from the same heroin supply, one will not be able to administer naloxone to the other. Or, in the case when opioid IDUs stagger their heroin injections and an IDU does not OD immediately, another IDU might struggle to give naloxone while under the influence of heroin. Similarly, OD Help users must have the app pre-downloaded, must register to use the app, and must have their cell phones charged and available. Furthermore, naloxone access laws vary state-by-state and might influence any user's participation with OD Help, whether the app user is an opioid user or a naloxone carrier.

Relying on a community-based context of use, the CRA understands opioid users and their contexts of opioid use, including the role of participation and availability of naloxone in the efficacy of their community-based approach. Mobility and credibility significantly factor into IDUs and other opioid users' contexts of use. The healthcare context of use is anchored to a particular physical location (St. Amant, 2017b, p. 112). The circumstances that might be present when an opioid user needs to administer naloxone are outside the conditions typically surrounding a medical encounter (e.g., a hospital room or physician's office). In fact, one of the CRA's goals is to get naloxone to opioid users wherever they are (e.g., on the street or at home). Each week, IDUs and opioid users are able to go physically to locations to receive naloxone and sterile intramuscular needles courtesy of the CRA's harm reduction program outreach by the CRA (and the laws that empower the CRA to act). The CRA's program and related naloxone and needle distribution and exchange are predictable and mobile—IDUs know when and where to obtain naloxone and needles to administer it in case of opioid OD. Conversely, OD Help uses existing mapping technologies to crowdsource a volunteer to deliver naloxone, which might already be in their possession or might need to be retrieved by the volunteer naloxone delivery driver. In either case, OD Help relies heavily on the willing participation and preparation of its existing networks—a risky reliance.

Distinct limitations exist for each approach because the context of use relies on the willingness and availability of participants to provide and administer naloxone as well as the multiple factors that require each method to work. However, the CRA's harm reduction program and PwrdBy's OD Help app provide new ideas and understandings about crowdsourced health crisis responses: opioid users' contexts of use (i.e., injection and pill, prescribed and illicit). An advantage of a community-based approach designed for users (or patients) in a healthcare context of use includes the membership in the very community the CRA serves (the social proximity, which suggests a relationship and some kind of existing credibility and trust with other users). For example, Kamenicky—the man who ODed in PwrdBy's OD Help instructional video—is also known as Ponytail Steve (Terry, 2010, para. 2). Ponytail Steve, a heroin addict, is sought by IDUs who are "desperate for [a Narcan] injection for a fallen buddy or lover of what some call the miracle drug" (para. 2) "between a dusty brickyard and rusty railroad tracks along the border of Chicago and blue-collar Cicero" (para. 1). Kamenicky lives in a tent encampment and he is the go-to guy for naloxone. Kamenicky, working with the CRA, is an embedded and a trusted member of the community the CRA serves. In other words, the CRA's community-based approach is internally participatory as well as propelled inwardly by its own community members and maintained by social proximity and trust.

Furthermore, the community-based approach is designed to use colloquial and engaging language to communicate with IDUs—an impact that constructs insider credibility or *ethos*. For example, the thumbnail for the CRA video on reversing opioid OD with

naloxone reads, "Hit 'em in the arm, thigh, or ass." Using "'em" instead of "them" reflects a conversational way of speaking, as does the inclusion of "ass" for "buttock" or "butt." The parallel structure of the three body parts is memorable too, as each word is only one syllable. And finally, although the CRA uses the generic naloxone vials for injection, in the video the naloxone is referred to as Narcan. Presumably, because naloxone is three syllables and Narcan is two syllables, the CRA (and IDUs) continue to refer to the naloxone as Narcan—it is simpler to say "Narcan" than "naloxone." The informal terminology is rooted in the IDU community that the CRA serves and the diction lends a particular kind of insider, relatable credibility—*ethos*—to the CRA and its harm reduction curriculum and outreach.

The technology-based approach is designed to tap into existing crowdsourced mapping technology (Uber, Lyft, and Rover.com) and local emergency medical services (911 and paramedics), which are networked systems. As such, OD Help clearly and easily connects with existing networks outside the immediate community of users. In other words, the technology-based approach is less rooted in a physical context of use than the CRA's community-based approach. As an advantage, then, the technology-based approach provides more expansive coverage, which does not depend on a single location. Instead, as conceptualized in the prototype, OD Help users can adjust the location of the maps in the app to expand or shrink the trusted naloxone carrier coverage area to provide opioid users with mobility outside their homes and their communities and allows them to access naloxone in less predictable physical locations. The OD Help app is a portable method of scouring for naloxone carriers within the app's network.

Because OD Help relies on existing technology, it also offers novel uses of those existing technologies' integrations with the app. For example, the OD Help prototype is connected to the breathing app Spire (see Figure 2), which monitors opioid users' breathing. In certain instances, because opioid users might be alone, Spire can track users' breathing and alert paramedics and members of opioid user's pre-loaded personalized network of friends and family in case of OD. Because the technology-based context of use design relies on existing networks, if "I'm fine" is not selected and the alert signal for help is not retracted, the app also automates the "get help" process once initiated, so the user can rely on the trusted network of naloxone carriers and the pre-loaded directory of friends and family to arrive and to reverse opioid OD.

Within the context of the current opioid epidemic, when health information is not "timely, accessible, accurate, useful, and understandable" (Melonçon, 2017, p. 24), the health information could contribute to the death of an opioid user. As heuristic categories for understanding and designing for users' contexts of use, participation, mobility, availability, and credibility are helpful to orient classifications for communication designers of healthcare information within the opioid epidemic context. These designers should consider several questions, including: *How will individuals participate using the healthcare information? What expectations are there for individuals who volunteer to participate in the opioid outreach? Is the outreach mobile, and if so, to what extent is the outreach mobile? For the outreach to work, what assumptions about outreach availability have been made? Who is responsible for delivering the outreach to users? What will compel individuals to participate in the outreach? How will participants demonstrate credibility or* ethos*?* These questions can provide insight into PXD's contexts of use for community-based and technology-based approaches in the opioid epidemic context, as well as in other health or medical-related contexts in which help is crowdsourced and "a continuum of active user participation" is required.

Public health scholars Brabham et al. (2014) point out, "In its most effective applications, crowdsourcing is a supplement to traditional, on-the-ground, face-to-face methods for participation, not [a] replacement" (p. 185). Toward the end of the CRA video, Kamenicky's (the man who ODed, or Ponytail Steve's) wife, Pamela, provides tips for viewers. She remarks, "Know where the nearest telephone is to dial 911" (CRA, 2010). Within the context of the FDA app-design contest, Pamela's comment is problematized and suggests two different kinds of "patients" or users in at least two disparate contexts for healthcare information design: individuals with immediate access to telephones and those with immediate access to connected smartphones. The latter is the assumed audience and context of use for OD Help; and the former is the assumed audience and context for the CRA. Regardless of the context of use, whether derived from a community or technology base, the digital divide generates users for each context. Our current opioid epidemic and attempts to expand access and use of naloxone to reduce harm from opioid use and OD need sensibly designed outreach programs and apps that are designed with PXD's contexts of use to alter the harmful effects of the current opioid epidemic.

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ENDNOTES

1. Please see the Appendix for a table of abbreviations.
2. All natural opiates and synthetic and semi-synthetic opiate derivatives are categorized as opioids and, whether taken medicinally or recreationally, highly addictive and potentially deadly.
3. By definition, OD means taking too much of a drug, whether dangerous and lethal or just temporarily debilitating. In all cases, OD does not necessitate death. I am grateful to Mike Jennings for pointing out this distinction. However, for the instances of OD in this article, I assume that opioid OD is dangerous and potentially lethal, which is why it has been identified as an epidemic.
4. Please see Gupta et al.'s (2016) *New England Journal of Medicine* article for a more complete history of naloxone and a discussion of the problematic rising costs of opioid antagonists associated with the opioid epidemic.
5. Non-expert users are individuals without formal medical, nursing, or emergency medical technician (EMT) or paramedic training.
6. According to the Urban Dictionary user NLR718, a cooker "is a spoon or bottle cap used to cook *drugs* such as *heroin*, coke [cocaine], meth [methamphetamine] to make it more pure and for junkies to get more hi [sic] it is soposed [sic] to cook the

the [sic] junk out of junk and bring out the pure quilitie [sic]" (2006, para. 2). See Cooker. (2006, July 15). Urban Dictionary. Retrieved from https://www.urbandictionary.com/define.php?term=cooker.

7. The curriculum is offered for free at www.anypositivechange.org/res.html

8. These individuals are affiliated with the CRA.

9. Currently (November 2018), the OD Help app remains available only as a prototype (J. Sheehan,personal communication, August 16, 2018). To develop OD Help, PwrdBy decided to partner with a technology organization in Canada: Brave. According to its Website, "Brave is a tech cooperative based in Vancouver BC. [They] build digital tools to keep people alive when they use drugs alone" (n.d., para. 1). Further, Brave works with other opioid harm reduction and de-stigmatization movements like PwrdBy. Although OD Help and its technology-based approach was absorbed into the Brave Button pilot project that currently exists solely in supportive housing conditions in Canada, the integrated technology- and community-based approach extracts the most effective design strategies from OD Help and draws upon a similar reliance on smartphones and technology to assist in cases of opioid OD. See Brave. (n.d.). Brave. Retrieved from https://www.brave.coop/

10. I am grateful to Laura Gurak, who pointed out social proximity among IDUs and the CRA.

NOTE

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APPENDIX

Organization or Term	Abbreviation
Cardiopulmonary Resuscitation	CPR
Centers for Disease Control and Prevention	CDC
Chicago Recovery Alliance	CRA
Food and Drug Administration	FDA
Harm Reduction Outreach Program	harm reduction program
Injection Drug User	IDU
International Patient Experience Design	I-PXD
National Institute on Drug Abuse	NIDA
Overdose	OD
Over-the-Counter	OTC
Patient Discharge Instructions	PDI
Patient Experience Design	PXD
Prescription Drug Abuse Policy System	PDAPS

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