# Responding to Opioid Overdoses and Treating Opioid Use Disorder: A Landscape Analysis of Chicago's West and South Side

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"We are failing in so many ways in understanding where people are and what they need in order to make a decision to go to treatment." – **Harm Reduction Provider** 

#### **SECTION 1: EXECUTIVE SUMMARY**

#### INTRODUCTION

The overdose crisis has been steadily on the rise for years both nationally and locally in Chicago, Illinois, exceeding deaths from vehicle accidents and gun violence. Alarmingly, overdose fatalities between January and June of this year have more than doubled compared to this same time period last year, resulting in 573 opioid-related deaths over the course of the first six months of 2020. While overdoses are experienced citywide, Chicago's West and South Sides are disproportionately burdened by overdose fatalities. Due to these inequities, this landscape analysis chose to focus on these geographic areas of Chicago.

Given the growing need and escalating loss of life, it is critical that our public health system move forward with a clear understanding of the existing gaps within our overdose prevention and opioid use disorder (OUD) treatment landscape. Best practices for preventing and responding to opioid-involved overdoses and treating OUD include broad access to naloxone (the opioid overdose antidote), medication for opioid use disorder (MOUD)—particularly agonist-based MOUD,<sup>3</sup> and coordinated transitions of care between service providing institutions.<sup>4</sup> It is through this intentional effort of identifying gaps in care, particularly as it relates to best practices, that this landscape analysis proceeded.

#### BACKGROUND AND PURPOSE: CDPH AND IPHI DATA

From May 2019 to January 2020, Chicago Department of Public Health (CDPH), in partnership with the Cook County Department of Public Health (CCDPH), conducted a hospital capacity assessment. This included data gathering from Cook County hospitals about current emergency department (ED) protocols and practices for responding to opioid overdoses, and engaging individuals with OUD in care. The original hospital capacity assessment was comprehensive and covered a variety of subject areas. Partial results of the assessment were shared with IPHI based on subject relevance and with the purpose of analyzing and incorporating the hospital capacity data into the landscape analysis.

Then, from June to July of 2020, the Illinois Public Health Institute (IPHI) conducted a series of key informant interviews as the second part of the landscape analysis project. This project was funded by CDPH via a Centers for Disease Control and Prevention (CDC) funded initiative. The interviews sought to identify service gaps and barriers for people at risk of overdose and people with an OUD through conversations with key stakeholders. Building off IPHI's Hospital Opioid Treatment and Response Learning Collaborative (HOTR-LC) objectives (refer to Appendix F), there was interest in better understanding current access to naloxone, MOUD, and continuity of care practices across Chicago's West and South Sides.

#### **METHODS**

This project utilized data provided by CDPH to determine both geographic focus and the categories of stakeholders to prioritize based on the areas and institutions experiencing the highest burden of overdose. The interviews focused on a sample of West and South Side ED-based hospital providers/administrators, opioid treatment programs (OTPs), federally qualified health centers and community health centers (FQHC/CHC), harm reduction service providers, and people who use drugs (PWUD) with treatment experiences.

Selection criteria for service provider stakeholders included:

- people who had been in their prospective roles for at least one year;
- people who had some direct service provision responsibilities (specific to overdose prevention and/or MOUD) rather than strictly administrator duties;
- for hospitals, the focus was specifically on individuals working in the ED or with some proximity to ED-related services; and
- people who were providing services to individuals who resided in Chicago, specifically on the West and South Sides, although many programs also had locations in other parts of the city or suburbs.

Some deviations from this plan were allowed given the short timeline and the increased challenges of connecting with frontline providers during COVID-19. The limitations are described in greater detail below.

Selection criteria for service users included:

- people with at least 2 years of lived experience which included people who were actively
  using illicit substances, and/or people formerly or currently engaged in treatment
  services; and
- people who lived on the West or South Side of Chicago

Over the course of four weeks beginning on Thursday, June 18th, 2020, IPHI conducted 25 qualitative interviews involving a combination of 27 service providers/program administrators

and PWUD. Figures 1 and 2 show the geographic spread of stakeholders interviewed across both South and West Side areas.

Figure 1.

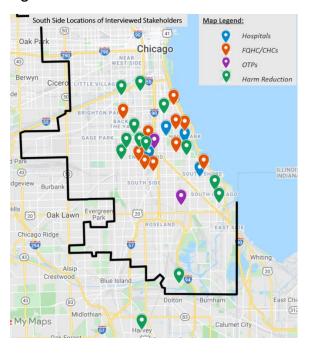


Figure 2.



#### **LIMITATIONS**

Regarding the hospital capacity assessment, there are some limitations worth noting.

- *Incomplete or duplicate hospital capacity assessment*: Forty-five hospitals initiated the assessment, while only 39 completed it.<sup>6</sup> Two of the hospitals that completed the assessment submitted duplicate entries and sometimes presented conflicting responses.
- Convenience sample of participants: In addition, while the hospital capacity assessment was intended for clinical leads of hospital EDs, the responses were dependent on the person completing the assessment and their familiarity or lack of familiarity with hospital protocols related to overdose prevention and MOUD. No data was collected on the person(s) who completed the assessment.

Regarding the stakeholder interviews, there are also some limitations worth highlighting.

• Limited time frame and convenience sample of participants: The timeframe for stakeholder interview completion was limited to one month. In addition, outreach to providers, particularly hospital-based providers was understandably challenging given the extraordinary pressures currently faced by hospitals and essential service providers

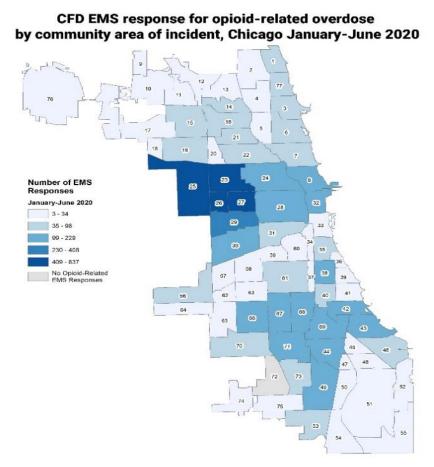
- because of the COVID-19 pandemic. Both factors meant that some flexibility measures were employed in the way of stakeholder recruitment and interview completion.
- *Diverse sample limits cross comparisons:* Finally, given the broad diversity among the stakeholders interviewed, there were some differences across the interview instruments used though all focused on the same general themes.

#### LANDSCAPE ANALYSIS FINDINGS

#### CDPH EPIDEMIOLOGICAL AND HOSPITAL CAPACITY ASSESSMENT DATA

#### Fatal and Non-fatal Overdose Trends

Figure 3.7



According to CDPH's Chicago Opioid Update Mid-Year report, Chicago experienced a 60% increase in EMS responses for opioid-related overdose events when comparing the first six months of 2019 to the first six months of 2020.8 Similarly, the data shows a 55% increase in Chicago overdose fatalities from 2019.9 Like the trends experienced over the last few years, 82.9% of fatal overdoses involved illicit opioids such as heroin and/or fentanyl, rather than prescription pain relievers or methadone, though an increase in methadone-involved

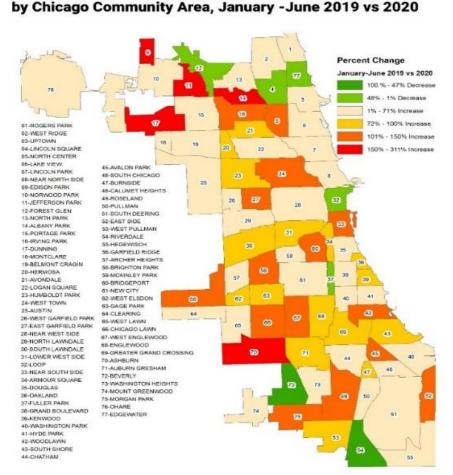
overdoses has increased compared to last year. <sup>10</sup> Seventy-six percent of overdose fatalities were among male-identified individuals with more than 75% of all fatalities occurring among adults

aged 35 to 74.<sup>11</sup> Just under 60% of all overdose deaths occurred among non-Latinx Black/African American persons, a figure that continues to rise among this group. In comparison, 26.4% of the opioid-involved overdose deaths occurred among non-Latinx white individuals, while 12.7% were among Latinx persons, and 0.9% among Asian or Pacific Islander persons.<sup>12</sup>

Figure 3 shows the Chicago community areas with the highest burden of EMS responses due to opioid-related overdose events between January and June of 2020. The West Side community areas of Austin, Humboldt Park, East and West Garfield Park are the most disproportionately impacted experiencing between 409-837 recorded EMS overdose incidents compared to other community areas experiencing as low as 3 overdose incidents.

Figure 4.<sup>13</sup>

Percent Change of Opioid-Related EMS responses



In comparison, Figure 4 shows the percent increase in EMS responses when comparing the first 6 months of 2019 to the first 6 months of 2020. Community areas that experienced the highest percent increase (150-311%) ranged from four North Side neighborhoods (Edison Park, Jefferson Park, Albany Park, and Dunning) to one South Side neighborhood (Ashburn). However, when compared to Figure 3, these same neighborhoods remained some of the least

impacted geographic areas with a maximum of 34 EMS responses among the North Side neighborhoods. Conversely, the one South Side neighborhood (Ashburn) experienced a higher burden of overdose, with a maximum of 98 overdose incidents by comparison. This same pattern

of disparity continues among the neighborhoods with the second and third highest percent increases and are further explored below.

#### Hospital Capacity Assessment Findings

Data on opioid overdose ED visits from 2017 to 2020 provided by the Illinois Department of Public Health (IDPH), identified Chicago's top 10 hospitals with the highest burden of overdose. This list is almost exclusively comprised of hospitals located on the city's West and South Sides. <sup>14</sup> Even within the list of top 10 hospitals, the differences in volume are stark. The hospital with the highest volume of overdoses in 2019 experienced 1,901 opioid-involved overdose ED visits, and over the first 8 months of 2020 experienced 1,076 opioid-involved overdose ED visits. Comparatively, the hospital with the lowest volume of overdose within the top 10 list experienced 407 ED visits in 2019. <sup>15</sup> Earlier 2017 opioid overdose volume data from IDPH reflecting a full 12-month period, shows just how dramatically opioid overdose-related ED visits have skyrocketed over the last few years. For example, when looking at the same West Side hospital with the highest burden of overdose in 2019 (n=1,901) and comparing those numbers to the data from 2017 (n=930), the percent increase is 104.41%. <sup>16</sup>

NALOXONE AND OVERDOSE PREVENTION ACCESS. Naloxone is the antidote for opioid overdose and access to the medication is a major area of concern. The hospital capacity assessment sought to gather information about existing overdose prevention training and education as well as naloxone prescribing and dispensing among hospital systems and providers.

#### OVERDOSE AND NALOXONE EDUCATION

When hospitals were asked if they had a protocol for either providing overdose prevention education internally or whether they referred patients for this, only 28.2% responded yes, that they did in fact have a protocol to educate patients or referred out.

#### NALOXONE PRESCRIBING

Regarding having actual protocols in place to prescribe naloxone, 56.4% of respondents said they did not have a protocol for this, while 23.1% responded either as unknown, in process of developing, or left their response blank.

#### NALOXONE DISPENSING

When a patient is given a prescription for naloxone, they must visit a pharmacy to receive the naloxone. Naloxone prescription rates can be as low as <1%.<sup>17</sup> Compared to naloxone prescribing, direct dispensing is a much more effective way of ensuring patients receive the medication in hand before discharge. Only 10.3% reported having a protocol that supported naloxone dispensing while 61.5% **did not**, and 28.2% either did not respond altogether or responded as unknown or in the process of developing. In terms of actual naloxone distributed to patients in the ED, only 7.7% reported actively dispensing directly to patients from the ED.

**MOUD ACCESS.** Regarding access to medications for opioid use disorder in the ED, several areas for improvement were identified including prescriber capacity, having an existing protocol, and services rendered.

#### PRESCRIBER CAPACITY

• According to hospital capacity assessment results, the number of providers who had a waiver to prescribe buprenorphine in the ED was incredibly low. Just under 72% of respondents either left their response blank or reported zero providers, while another 17.9% reported having between one and five providers who could prescribe buprenorphine. Roughly 3% percent reported between six and 10 providers, and only 7.7% reported having between 11 and 15 providers in the ED with a buprenorphine waiver.

#### EXISTING PROTOCOL

Hospitals were asked if they currently had a protocol for prescribing buprenorphine. Only 5.1% responded that they did compared to 59% who responded they did not, and the remaining 33.3% who responded as either unknown, in the process of developing, or did not answer the question.

#### SERVICES RENDERED

• Finally, when asked about the number of buprenorphine prescriptions provided in the ED for OUD within the previous year, 2018, 92% of respondents either reported 0, left their response blank or responded that they did not know. Comparatively, only 5% reported between one and five buprenorphine prescriptions given in 2018, and only 3% reported 40.

#### STAKEHOLDER INTERVIEWS

A number of findings emerged from the stakeholder interviews. In short, *sufficient access to* overdose prevention and treatment services remain a critical gap in our city's landscape and infrastructure during a time in which overdoses and overdose deaths are at an all-time high.

Major themes identified included barriers related to access, continuity of care, structural barriers, service user factors and experiences, and COVID-19. Within these major themes, there were five most frequently cited barriers which are illustrated through stakeholder interview quotes below. Frequently cited barriers included: Service user readiness, general stigma toward PWUD, lack of formalized care coordination systems, overall resource scarcity, and co-occurring mental health needs among service users and lack of behavioral health integration.

Service user readiness to change was one of the most frequently cited barriers however was discordant with all the structural and access barriers identified. What was more salient was the understanding that the existing system of care for people at risk of overdose and people with OUD is in fact not "ready" for many service users when they are ready, leaving many to fall through the cracks due to a variety of institutional, practice, and system-level barriers. Similarly, access barriers and readiness beliefs were often shaped by general stigma toward PWUD. Various examples of stigma were provided by both providers and PWUD alike, highlighting the pervasiveness with which discrimination against PWUD thrives across helping systems. The lack of formalized care coordination to aid in transitions of care between institutions was frustrating for providers and often resulted in poor outcomes among patients. Systems that do not talk to each other result in patients getting lost in the shuffle rather than getting the care they need. An overall need for greater resource investment to strengthen existing services was also common. The idea that the resources programs had at their disposal were never enough to meet the need was also expressed. Mention of the presence of co-occurring mental health conditions was common in the context of a contributing factor to substance use that often goes untreated due to poorly designed treatment systems that lack the capacity to treat the whole person.

#### STAKEHOLDER NALOXONE AND MOUD PROVISION

• Limited Emergency Department Naloxone Access Points. Out of 19 programs interviewed, harm reduction programs and opioid treatment programs (OTPs) were the most likely entities to be distributing naloxone directly to PWUD and people at risk of overdose in the form of a take-home kit, with one primary harm reduction program serving as a centralized backbone for the provision of naloxone supplies. As a result of Governor Pritzker's Executive Order from January of this year, which was intended to increase support to address the overdose crisis, additional funding was provided to increase naloxone access to community residents. Some of this naloxone went to OTPs for the distribution of naloxone directly to service users. Earlier this year, IDHS/SUPR, conducted a survey of local OTPs to assess overdose prevention service capacity via

naloxone distribution. Results from that survey demonstrate that only 34% of the 50 OTPs surveyed reported already distributing naloxone to patients prior to these recent investments and prior to the onset of COVID-19.<sup>19</sup> In addition, the Federally Qualified Health Centers (FQHCs) and Community Health Centers (CHCs) who were interviewed all reported prescribing naloxone while four of the five reported also providing direct distribution of take-home kits when prescribing was a barrier. **Only one of the seven hospitals IPHI interviewed reported distributing naloxone directly to patients from the ED.** Two hospitals reported prescribing while one of the two reported that their hospital was in the process of piloting a direct distribution program out of the ED as well as in outpatient settings. The remaining four hospitals reported no naloxone access point from the ED.

Delayed Medication for Opioid Use Disorder Initiation Across All Providers. Out of seven hospitals interviewed, three were initiating buprenorphine treatment within the ED, however, two of the three programs had only recently begun providing this service. One additional hospital reported having a doctor on staff who could prescribe. Unfortunately, the practice was not widespread or standardized among other physicians. Finally, the three remaining hospitals reported that their EDs were not initiating buprenorphine treatment from the ED at this time. Out of nine community-based treatment providers interviewed, a wide range of medication (namely methadone and buprenorphine) wait times were reported ranging from one day to one week. Only two out of nine community-based treatment providers reported consistently getting service users MOUD either the same day or next day.

#### **EMERGING THEMES: BARRIERS**

A variety of themes broadly focused on barriers were also identified. Key findings related to one of the following major themes:

- 1) access barriers,
- 2) continuity of care barriers,
- 3) structural barriers,
- 4) service user factors and experiences, and
- 5) COVID-19 pandemic-related barriers.

Each major theme is further defined by subthemes and specific examples that are highlighted below. Moreover, the 5 most frequently cited barriers that were identified in roughly half of all the interviews are highlighted below via illustrative quotes. Each of these issues was described as a barrier to service engagement.

- 1. ACCESS BARRIERS. Barriers of access were the largest category and can be better understood through a series of sub-themes including barriers of MOUD availability, high threshold service model barriers for MOUD, stigma, and limited naloxone access.
  - a. MOUD AVAILABILITY-RELATED ACCESS BARRIERS. Availability-related barriers included examples such as limited prescriber availability which greatly limited MOUD initiation, treatment availability for uninsured individuals, and waitlists for treatment programs or residential facilities. Limited clinic hours were also discussed in the context of limited prescriber availability if for example, individuals could only gain access to medication after seeing a prescriber and that prescriber was only scheduled to work at the program two days each week.
  - b. HIGH THRESHOLD SERVICE MODEL BARRIERS FOR MOUD. In the social service field, the terms "high threshold" and "low threshold" are often used to denote whether the barrier the point of entry to services is high or low. 20 High threshold service model barriers for MOUD included things like technology, travel, and identification requirements that limited access. Counseling requirements were another major issue as providers and programs often require counseling to initiate treatment and/or continue treatment. Having reliable transportation was commonly mentioned as was the requirement among methadone clinics that service users visit daily to get dosed. Furthermore, many stakeholders spoke about individual will and individual desire as a critical factor to engage in treatment services. This was described as a "readiness to change". This emphasis on individual readiness sometimes conflicted with structural-level barriers presented by stakeholders.
  - c. STIGMA FROM PROVIDERS. Stigma on the part of healthcare and treatment providers is pervasive and well documented in the literature. Stigma was a major and recurring theme among stakeholders that included a general resistance toward working with PWUD and toward MOUD. Providers were described as having regressive attitudes toward PWUD and OUD that influenced their interaction with service users. This included beliefs around PWUD being undesirable, dishonest, and/or unruly people. It included negative beliefs around MOUD such as the idea that medication for people with OUD is enabling drug use and simply substituting one drug for another or that medication alone is ineffective despite the evidence.

- d. LIMITED NALOXONE ACCESS. Among the stakeholders interviewed, the setting with the least access to naloxone for patients was hospital EDs. However, providers across settings spoke about ongoing barriers to naloxone access due to cost and regulatory challenges, limitations due to prescribing, and limited opportunities for secondary exchange.
- 2. CONTINUITY OF CARE BARRIERS. Barriers related to formalized linkage systems that seek to ensure continuity of care, was another salient theme highlighted by stakeholders.
  - a. ABSENCE OF ROBUST CARE COORDINATION SYSTEMS. This was described as an overall lack of discharge planning and follow up, an over-reliance on referrals rather than warm hand-offs, and informal partnerships when some level of crosssector collaboration was identified. Some providers talked about the challenges of receiving a patient with complicated and/or multiple needs without any coordination or basic information about the patient such as medical records, specialty service needs, ID or insurance information.
- 3. STRUCTURAL BARRIERS. Structural barriers were often identified and included a variety of social equity issues like housing access, food insecurity, unemployment, and criminalization of substance use, which interviewees described as major barriers to prevention and treatment system engagement. Additionally, system-level barriers due to limited health system integration, and regulatory and financial barriers were referenced as further impediments to resource access.
  - a. SOCIAL AND STRUCTURAL INEQUITY. This included broad resource scarcity regarding available services as well as population needs including things like housing access, poverty and unemployment, food insecurity, and criminalization of substance use. Stakeholders often described the needs of the community and people they were serving as much greater than their organization's capacity to meet that need. Social and structural inequity was discussed as barriers that prevent people from participating fully in the treatment system and/or from gaining access altogether.
  - b. LIMITED HEALTH SYSTEM INTEGRATION. Limited health system integration was expressed as a common explanation for gaps in service between behavioral health and primary health care as well as between mental health and substance use service systems. Some stakeholders spoke to a need for a whole health

- approach that addressed the needs of the person seeking services in a comprehensive way.
- c. **REGULATORY AND FINANCIAL BARRIERS**. Examples of regulatory and financial barriers included federal DEA regulations that limit MOUD access overall, waiver barriers for buprenorphine prescribing, and naloxone purchasing. <sup>22</sup> Methadone treatment involved other barriers such as the strict requirements for getting in the door (i.e. proof of ID, ability to pay or proof of insurance) and the requirements around supervision of medication intake (i.e. daily visits to the methadone clinic) that can be a logistical barrier for many service users.
- 4. SERVICE USER FACTORS AND EXPERIENCES. Service user factors and experiences comprised internalized stigma, descriptions of a low self-concept, and misinformation factors shared by stakeholders. Co-occurring mental health needs were also commonly raised throughout the interviews. These factors do influence a person's insight, motivation, and desire to seek treatment, however, given the lack of power most service users have over the treatment system, these factors should be understood as a consequence of marginalization rather than a cause of it.
  - a. INTERNALIZED STIGMA, SELF-CONCEPT, AND MISINFORMATION FACTORS. This section was important to draw attention to because the shame often internalized by PWUD and the myths around MOUD perpetuated by society that service users often adopt, all contribute to this idea of internalized or self-stigma<sup>23</sup> that ultimately results in delaying or altogether avoiding service engagement. Given all the misinformation that health providers, not to mention the general public, espouses, and add onto that the stigma providers and the public often perpetuate around substance use, it should be no surprise that PWUD often internalize those same messages. Such dynamics are not uncommon among groups experiencing marginalization yet can contribute to profound psychological hardship.<sup>24</sup>
  - b. CO-OCCURRING MENTAL HEALTH NEEDS. This was a common theme that came up in several interviews as a contributing factor to substance use and substance misuse. Nearly all of the service users interviewed raised their own mental health needs as a contributing factor to their use, and/or as a significant need they felt substance use treatment should address and often did not. Some service users also shared about the trauma of surviving an overdose and/or the trauma of losing a loved one to an overdose.

- **5.** COVID-19 PANDEMIC-RELATED BARRIERS. COVID-19 barriers centered on changes in service availability overall due to physical distancing safety regulations and communication barriers due to limited technology access on the part of service users.
  - a. COVID-19-SPECIFIC BARRIERS. An overall loss of access to services was the main challenge identified related to the pandemic. Specifically, the loss of walk-in access that some clinics and programs employed prior to the outbreak, the loss of in-person provider visits that have resulted in delayed care, and increased wait times for receiving MOUD.

#### **RECOMMENDATIONS**

#### RESOURCE ALLOCATION FOR NEW AND EXISTING SERVICES, ADOPTION OF LOW-THRESHOLD MODELS, AND SUSTAINED POLICY CHANGE.

More evidence-based programs and services for substance use disorder (SUD), particularly OUD, are simply required to meet the need. One great example of this was the investment made earlier this year because of Governor Pritzker's Executive Order to address the overdose crisis, whereby OTPs received naloxone to distribute directly to their clients. The hope is that this new investment in resource allocation can be sustained over time, becoming part of the city and state's permanent overdose prevention and response strategy.

FREE, ON DEMAND, AND UNLIMITED NALOXONE AND MOUD. Life-saving medications like MOUD and naloxone must be made widely available, regardless of one's ability to pay, and must include all relevant healthcare entities as well as jail and prison populations. PWUD and their loved ones should have multiple naloxone access points at their disposal that prioritize an unlimited, secondary exchange model of distribution.<sup>25</sup> All MOUD-based treatment should adopt and adhere to a low-threshold model as well that ensures same-day access to medication and allows for walk-ins.<sup>26</sup>

# CAPACITY DEVELOPMENT VIA TRAINING, PEER WORKFORCE DEVELOPMENT, AND STIGMA REDUCTION.

Widespread implementation of evidence-based curriculum on substance use and misuse that addresses stigma is needed across all healthcare sectors - primary care, behavioral health, pharmacy, criminal justice and judicial systems, and social services.<sup>27</sup>,<sup>28</sup> Investing in the peer recovery workforce is another important way to build capacity and reduce stigma. Incorporating peer workers into the service environment benefits service users by helping advocate for patient rights and needs while also helping to educate their provider colleagues along the way. <sup>29</sup>

■ INTEGRATE HARM REDUCTION AND TRAUMA-INFORMED CARE INTO RECOVERY AND TREATMENT FRAMEWORKS. Recovery must be client-centered and client-defined, rather than restricted to narrow definitions centered around abstinence-only metrics that are not evidence-based and perpetuate stigma and fail to recognize the needs, realities, and preferences of service users. Many people with a SUD also have trauma histories yet substance use treatment often lacks a trauma-informed approach. Training on harm reduction and trauma-informed care should be required for all providers working in the substance use field. In addition, patient outcomes should be reconfigured to support incremental change.

#### DECREASE SOCIAL INEQUITY - HOUSING AND CRIMINALIZATION.

People with a SUD are marginalized because their condition, which relies on the consumption of illicit substances, is illegal. This is not the case with any other health condition.

• SUPPORT DRUG DEFELONIZATION IN ILLINOIS. As a move toward broader decriminalization reform, local advocates have been working to pass a state law that reduces penalties for possession of small amounts of illicit substances from a felony to a misdemeanor.<sup>31</sup>

Criminalization of substance use is also one of the biggest barriers to housing that PWUD experience. Increasing the number of recovery homes<sup>32</sup> and housing first programs<sup>33</sup> for people with SUDs is critical.

REFORMING RECOVERY HOMES TO SUPPORT MOUD. State Opioid Response (SOR) grants should fund the development of new recovery homes that support MOUD.<sup>34</sup>
 Additionally, capacity development among existing recovery homes that are publicly funded should be prioritized and should include work plans that move recovery homes toward best practice models by changing policies and practices.

#### INCREASE SYSTEM INTEGRATION TO STRENGTHEN TRANSITIONS OF CARE.

While there are a number of integrated care models<sup>35</sup>, what is widely accepted are the benefits and improved outcomes of aligning mental health and substance use care with primary care.<sup>36</sup>,<sup>37</sup> Integrated care models have been shown to increase access to services, reduce costs, and improve the quality of care received by patients.<sup>38</sup> Working with local hospitals and community-based providers to move toward a more integrated system of care would increase capacity by building on the strengths of existing services and would provide a better healthcare experience for service users as well as providers.

#### REGULATORY CHANGES TO INCREASE MOUD ACCESS.

While many barriers are due to prohibitive federal regulations that are beyond the scope of state-level reforms, it remains important to highlight the policy barriers that impede access on a

national level and emphasize the significance of states advocating for federal-level reforms such as those mentioned here.

- MAKE COVID-19 MOUD CHANGES PERMANENT. The recent regulatory changes that loosened restrictions around MOUD because of COVID-19, have been a major step forward in increasing access to care and should be made permanent.
- ELIMINATE X WAIVER REQUIREMENTS. Elimination of the X waiver requirement for buprenorphine prescribing and the limits on the number of buprenorphine patients a prescriber can be treating at one time is needed to improve access and reduce overdose mortality. 39
- END METHADONE REGULATIONS THAT PREVENT ACCESS IN PRIMARY CARE SETTINGS. Advocacy efforts should include loosening federal regulations that inhibit methadone access as well by moving to eliminate methadone restrictions in primary care settings<sup>40</sup>.
- OVER-THE-COUNTER (OTC) NALOXONE. Naloxone's status as a prescription drug should be modified so that the medication can be approved as an OTC medication.<sup>41</sup>
- MEDICAID BILLING. States must work with their local Medicaid programs to address reimbursement barriers that impact billing for evidence-based interventions such as overdose education and naloxone distribution across hospital settings.<sup>42</sup>

"So many people that I've known personally over the course of my life they're gone, they're dead ya know, including my wife. And I've lost so many people and still continue to lose people that I know. It's crazy. I can't even wrap myself around it at times. It's hard to do. I don't really try to take the time to wrap myself around it because it's just too much, you know, to try to grasp that." – Service User

#### **SECTION 2: INTRODUCTION**

The overdose crisis has been steadily on the rise for years both nationally and locally in Chicago, Illinois, exceeding deaths from vehicle accidents and gun violence.<sup>43</sup> Alarmingly, overdose fatalities between January and June of this year have more than doubled compared to this same time period last year, resulting in 573 opioid-related deaths over the course of the first six months of 2020.<sup>44</sup> While overdoses are experienced citywide, Chicago's West and South Sides are disproportionately burdened by overdose fatalities. Due to these inequities, this landscape analysis focuses on these geographic areas of Chicago.

Given the growing need and escalating loss of life, it is critical that our public health system move forward with a clear understanding of the existing gaps within our overdose prevention and OUD treatment and response landscape. Best practices for preventing and responding to opioid-involved overdoses and treating OUD include broad access to naloxone (the opioid overdose antidote), MOUD—particularly agonist-based MOUD,<sup>45</sup> and coordinated transitions of care between service providing institutions.<sup>46</sup> It is through this intentional effort of identifying gaps in care, particularly as it relates to best practices, that this landscape analysis proceeded.

# SECTION 3: BACKGROUND AND PURPOSE: CHICAGO DEPARTMENT OF PUBLIC HEALTH AND ILLINOIS PUBLIC HEALTH INSTITUTE DATA

The term 'overdose' rather than 'opioid' is used in this report to account for all overdose incidents. Although most recorded overdose incidents have involved a licit or illicit opioid, polysubstance use is not uncommon<sup>47</sup> and can be a contributing factor of an overdose incident. Thanks to lifesaving interventions that take place in both medical and community settings, many overdose incidents are survived. While the number of total overdose incidents is challenging to track due to underreporting and community-based interventions, the city of Chicago and the state of Illinois are conducting regular surveillance of calls to emergency medical services (EMS) for overdose incidents and actual deaths from overdoses. Utilizing CDPH's most recent report on

overdose trends, this report includes some background on the overdose crisis as it stands in Chicago. The Department also shared some of the results from a recent hospital capacity assessment conducted by CDPH that provides further context for this landscape analysis.

From May 2019 to January 2020, CDPH, in partnership with the Cook County Department of Public Health (CCDPH), set out to gather data from Cook County hospitals about current emergency department (ED) protocols and practices for responding to opioid overdoses, and engaging individuals with OUD in care. <sup>48</sup> The original hospital capacity assessment was comprehensive and covered a variety of subject areas. Partial results of the assessment were shared with IPHI based on subject relevance and with the purpose of analyzing and incorporating them into the landscape analysis.

Then, from June to July of 2020, the Illinois Public Health Institute (IPHI) conducted a series of key informant interviews as the second part of the landscape analysis project. This project was funded by CDPH via a CDC funded initiative. The interviews sought to identify service gaps and barriers for people at risk of overdose and people with an OUD through conversations with key stakeholders. Building off IPHI's Hospital Opioid Treatment and Response Learning Collaborative (HOTR-LC) objectives (refer to Appendix F), there was interest in better understanding current access to naloxone, MOUD, and continuity of care practices across Chicago's West and South Sides.

#### **SECTION 4: METHODS AND LIMITATIONS**

#### **OVERVIEW OF METHODS**

This project utilized data provided by CDPH to determine both geographic focus and the types of stakeholders to prioritize based on the areas and institutions experiencing the highest burden of overdose. Having access to the hospital capacity data in advance allowed IPHI to focus on questions about barriers which complemented the findings from the hospital capacity assessment (refer to Appendices A-E). As a result, the interviews focused on a sampling of West and South Side ED-based hospital providers/administrators, OTPs, FQHC/CHC, harm reduction service providers, and PWUD with treatment experiences. It should be noted that a variety of terms and acronyms are used interchangeably throughout this report to refer to both individuals at risk of overdose (i.e. patients, clients, service users, PWUD, people with a SUD, people with an OUD) and medication-based treatment (i.e. Medication assisted treatment (MAT) and MOUD).

Selection criteria for service provider stakeholders included:

people who had been in their prospective roles for at least one year,

- people who had some direct service provision responsibilities (specific to overdose prevention and/or MOUD) rather than strictly administrator duties, and
- for hospitals, the focus was specifically on individuals working in the ED or with some proximity to ED-related services.
- people who were providing services to individuals who resided in Chicago, specifically on the West and South Sides, although many programs also had locations in other parts of the city or suburbs.

The decision to focus on EDs for the hospital interviews was based on the understanding that there has been less OUD service infrastructure development in the ED compared to other hospital settings. The ED is also a common touch point for many people at risk of overdose. Some deviations from this plan were allowed given the short timeline and the increased challenges of connecting with frontline providers during COVID-19. The limitations are described in greater detail below.

Selection criteria for service users included:

- people with at least 2 years of lived experience which included people who were actively using illicit substances, and/or people formerly or currently engaged in treatment services, and
- people who lived on the West or South Side of Chicago

Over the course of four weeks beginning on Thursday, June 18th, 2020, IPHI conducted 25 qualitative interviews involving a combination of 27 service providers/program administrators and PWUD. Interview subjects were a mix of previously known institutions or individuals as well as institutions and individuals not previously known to IPHI staff. The 25 interviews spanned a diverse group of South and West Side providers and PWUD. Figures 1 and 2 show the geographic spread of stakeholders interviewed across both South and West Side areas. A greater number of institutional markers is noted on the two maps to reflect the fact that some service providing institutions had multiple locations. Finally, it is important to note that the stakeholder interviews focused on ED capacity given the growing evidence demonstrating the impact of ED-based naloxone and MOUD access. For this reason, findings are not reflective of services that may be offered in other hospital settings such as inpatient and outpatient settings.

Figure 1.

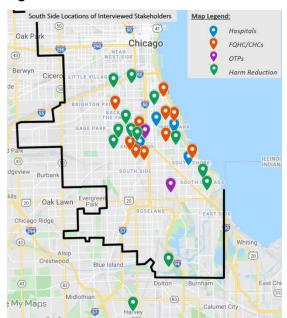


Figure 2.



#### STAKEHOLDER INFORMATION: PROVIDERS, PROGRAM ADMINISTRATORS AND PWUD

#### Hospitals

- o Nine providers/administrators were interviewed across seven hospitals.
- o Two of the nine individuals had been in their role for less than one year.
- o Five of the nine were working in a role specific to the ED.
- o Four identified direct care provider responsibilities while five identified strictly administrator, managerial or faculty duties.

#### ■ FQHC/CHCs

- o Five individuals across five different programs were interviewed.
- o All five had been working in their role for a year or more.
- All held combination roles that included some direct care provision as well as some administrator or managerial duties.

#### OTPs

- o Four individuals were interviewed across four OTP programs.
- Only one of the individuals had been in their role for less than a year.
- Three were administrators while one had a combination role including some direct service provision in addition to some administrative duties.

#### Harm Reduction Service Providers

- o Four individuals were interviewed across three different programs.
- o All the individuals had been in their roles for many years.

o Three individuals were solely direct service providers while one individual held a combination role that included both research and administrative responsibilities.

#### PWUD

- Five individuals were interviewed. These were individuals who the interviewer had previous relationships with and were recruited through a harm reduction organization. All individuals were currently using and had been for 10 years or longer.
- All individuals had current or previous experiences with treatment systems in Chicago.

All interviewed persons and institutions were chosen due to their location on the West and South Side. Recruitment of interview participants was also influenced by some previous relationships held by the interviewer as having a prior relationship increased access. Interview questions were not provided to the interviewees in advance. All interviews were conducted virtually via Zoom Video Conferencing or via conference call and were about a half hour in duration.

#### STAKEHOLDER INTERVIEW BACKGROUND

The purpose of these interviews was to gain a broad sense of both current capacity and barriers to care on Chicago's West and South Sides by speaking to frontline providers and PWUD who were currently or had recently been treatment service users. Aside from simple background questions about the interviewee's role and responsibilities, all questions for service providers were framed around three main best practice areas: naloxone provision, MOUD provision, and continuity of care systems. Questions were designed to solicit barriers to all of these best practices. Interview participants were also asked about what they thought was missing for PWUD/people with OUD and what was needed to adequately meet their needs.

- The hospitals, FQHCs/CHCs, OTPs, and harm reduction service providers that were interviewed were either already disseminating naloxone or had the potential to disseminate naloxone. Therefore, interviewees were asked about whether naloxone was being provided to service users. If so, interviewees were asked to identify whether dissemination was happening via prescription or directly by kit. Participants were also asked to describe barriers to providing naloxone to service users.
- The hospitals, FQHCs/CHCs, and OTPs that were interviewed were either already MOUD
  providers or had the potential to be MOUD providers (i.e. hospital-based providers). For
  this reason, many of the interview questions asked about whether MOUD was offered,
  the average length of time for someone to begin receiving medication, and the barriers

- that stand in the way of getting people access to MOUD as well as barriers to retaining service users in care.
- Providers were also asked about existing partnerships as it related to addiction care and harm reduction services and the barriers that stood in the way of successful linkage systems to ensure continuity of care.
- Current and former service users were also interviewed and asked about experiences with harm reduction and treatment services.

#### **LIMITATIONS**

Regarding the hospital capacity assessment, there are some limitations worth noting.

- *Incomplete or duplicate hospital capacity assessment*: Forty-five hospitals initiated the assessment, while only 39 completed it.<sup>49</sup> Two of the hospitals that completed the assessment submitted duplicate entries and sometimes presented conflicting responses. Therefore, some of the data presented may not total 100% largely due to a common 3% of duplicate responses that presented conflicting answers.
- Convenience sample of participants: In addition, while the hospital capacity assessment was intended for clinical leads of hospital EDs, the responses were dependent on the person completing the assessment and their familiarity or lack of familiarity with hospital protocols related to overdose prevention and MOUD. No data was collected on the person(s) who completed the assessment.

Regarding the stakeholder interviews, there are also some limitations worth highlighting.

- Limited time frame and convenience sample of participants: The timeframe for stakeholder interview completion was limited to one month. In addition, outreach to providers, particularly hospital-based providers was understandably challenging given the extraordinary pressures currently faced by hospitals and essential service providers because of the COVID-19 pandemic. Both factors meant that some flexibility measures were employed in the way of stakeholder recruitment and interview completion. For example, while the interview preference and outreach were mostly focused on direct service providers, the actual people interviewed comprised a mix of administrators, direct service providers, and individuals with combination roles. Recruitment was often subject to who could be accessed, especially when a prior relationship did not exist. Therefore, the information gathered was influenced by the individuals interviewed and their proximity or lack of proximity to direct service provision.
- *Diverse sample limits cross comparisons:* Finally, given the broad diversity among the stakeholders interviewed, there were some differences across the interview instruments used though all focused on the same general themes.

#### SECTION 5: LANDSCAPE ANALYSIS FINDINGS

"Within the community and with other providers they make them [patients] jump through so many hoops like they need to do an initiation visit and then they need to do a drug screen and then they are required to go to counseling and then once they go they can follow up in two weeks and then get their medication. We don't do that with a patient with diabetes right, like that would be medical malpractice. If they came in with an A1C of 12 and then we said, 'Oh you have to go to a nutritionist first and then you have to get labs done and then follow up in two weeks and then I'll give you medicine.' I would've lost my license." – FQHC/CHC Provider

#### CDPH EPIDEMIOLOGICAL AND HOSPITAL CAPACITY ASSESSMENT DATA

#### FATAL AND NON-FATAL OVERDOSE TRENDS

According to CDPH's Chicago Opioid Update Mid-Year report, Chicago experienced a 60% increase in EMS responses for opioid-related overdose events when comparing the first six months of 2019 to the first six months of 2020. 50 Similarly, the data shows a 55% increase in Chicago overdose fatalities from 2019.<sup>51</sup> About 60% of all overdose deaths involved opioids alone, which demonstrates the prevalence and significance of poly-substance use, particularly cocaine. 52 Like the trends experienced over the last few years, 82.9% of fatal overdoses involved illicit opioids such as heroin and/or fentanyl, rather than prescription pain relievers or methadone though an increase in methadone-involved overdoses has increased compared to last year.<sup>53</sup> Seventy-six percent of overdose fatalities were among male-identified individuals with more than 75% of all fatalities occurring among adults aged 35 to 74.54 Just under 60% of all overdose deaths occurred among non-Latinx Black/African American persons, a figure that continues to rise among this group. In comparison, 26.4% of the opioid-involved overdose deaths occurred among non-Latinx white individuals while 12.7% were among Latinx persons, and 0.9% among Asian or Pacific Islander persons. 55 These numbers reflect significant increases among Black/African American individuals, some increases among Asian individuals and decreases among white and Latinx groups.

Figure 3.56

#### CFD EMS response for opioid-related overdose by community area of incident, Chicago January-June 2020

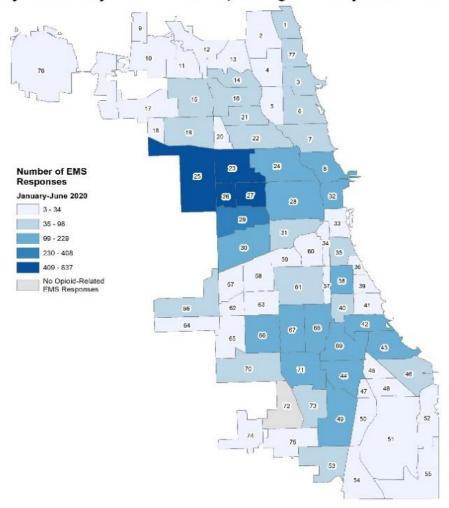


Figure 3 shows the Chicago community areas with the highest burden of EMS responses due to opioid-related overdose events between January and June of 2020.

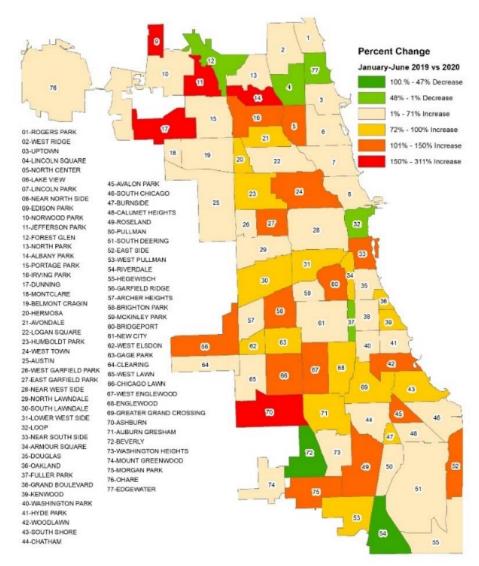
The West Side community areas of Austin, Humboldt Park, East and West Garfield Park are the most disproportionately impacted experiencing between 409-837 recorded EMS overdose incidents compared to other community areas experiencing as low as 3 overdose incidents.

In comparison, Figure 4 shows the percent increase in EMS responses when comparing the first 6 months of 2019 to the

first 6 months of 2020. Community areas that experienced the highest percent increase (150-311%) ranged from four North Side neighborhoods (Edison Park, Jefferson Park, Albany Park, and Dunning) to one South Side neighborhood (Ashburn). However, when compared to Figure 3, these same neighborhoods remained some of the least impacted geographic areas with a maximum of 34 EMS responses among the North Side neighborhoods. Conversely, the one South Side neighborhood (Ashburn) experienced a higher burden of overdose, with a maximum of 98 overdose incidents by comparison. This same pattern of disparity continues among the neighborhoods with the second and third highest percent increases and are further explored below.

Figure 4.<sup>57</sup>

#### Percent Change of Opioid-Related EMS responses by Chicago Community Area, January -June 2019 vs 2020



The neighborhoods that experienced the 2<sup>nd</sup> greatest range increase (101% to 150%) included 15 neighborhoods and spanned the entire city. Similarly, the North Side neighborhoods in this category were less impacted compared to some of the West and South Side communities. For example, East Garfield Park already ranked as one of the top 4 communities in 2020, with some of the highest numbers of EMS calls, and experienced a 101-150% increase in EMS responses for overdoses when comparing 2019 to 2020. Likewise, the South Side neighborhoods of Chicago Lawn, West Englewood, Woodlawn and Roseland also

experienced significant increases having ranked as neighborhoods with the third highest number of EMS responses in 2020. Finally, there were 16 neighborhoods, also spread out across the city, that saw the third greatest increase ranging from 72-100%. Again, a similar pattern emerged in that the North Side neighborhoods showed a less disproportionate impact when compared to the West and South Side community areas such as Humboldt Park, South Lawndale, Englewood, Greater Grand Crossing, West Pullman, South Shore and Auburn Gresham.

#### HOSPITAL CAPACITY ASSESSMENT FINDINGS

Data on opioid overdose ED visits from 2017 to 2020 provided by the Illinois Department of Public Health (IDPH), identified Chicago's top 10 hospitals with the highest burden of overdose. This list is almost exclusively comprised of hospitals located on the city's West and South Sides. <sup>58</sup> Even within the list of top 10 hospitals, the differences in volume are stark. The hospital with the highest volume of overdoses in 2019 experienced 1,901 opioid-involved overdose ED visits, and over the first 8 months of 2020 experienced 1,076 opioid-involved overdose ED visits. Comparatively, the hospital with the lowest volume of overdose within the top 10 list experienced 407 ED visits in 2019. <sup>59</sup> Earlier 2017 opioid overdose volume data from IDPH reflecting a full 12-month period, shows just how dramatically opioid overdose-related ED visits have skyrocketed over the last few years. For example, when looking at the same West Side hospital with the highest burden of overdose in 2019 (n=1,901) and comparing those numbers to the data from 2017 (n=930), the percent increase is 104.41%. <sup>60</sup>

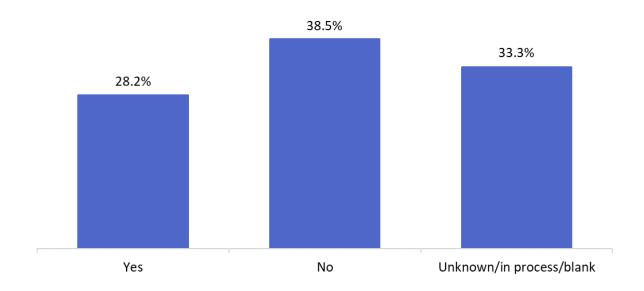
It is worth emphasizing that these numbers only represent ED-based overdose data and as such do not fully reflect the need for OUD specific services. Many individuals at risk of overdose or with OUD have co-occurring conditions, and/or cycle in and out of hospitals due to sickness from withdrawal. Moreover, while the overdose crisis is a citywide crisis and hospital EDs across the county are all experiencing increases, a geographic burden clearly exists. In the middle of a global pandemic, many West and South Side communities who already face inadequate resources, what some refer to as health care deserts, <sup>61</sup> are forced to battle an overdose crisis that is disproportionately killing older, Black/African American men. Therefore, the need for bolstering existing OUD services across hospital and community settings as numbers continue to rise cannot be overstated.

*Naloxone and Overdose Prevention Access.* As the antidote for opioid overdose, naloxone access is a major area of concern. The ED hospital capacity assessment sought to gather information about existing overdose prevention training and education as well as naloxone prescribing and dispensing practices among hospital systems and providers.

#### OVERDOSE AND NALOXONE EDUCATION

Beginning with overdose and naloxone education, only 33.3% of respondents said there was education provided in the ED for staff compared to 38.5% which responded that there was not, and 25.6% which reported their answer as either unknown, in the process of developing, or did not answer the question altogether. When hospitals were asked if they had a protocol for either providing overdose prevention education internally or whether they referred patients for this, only 28.2% responded yes, that they did in fact have a protocol to educate patients or referred out.

Percentage of hospitals that have a protocol for providing in-person overdose prevention education or referring patients.

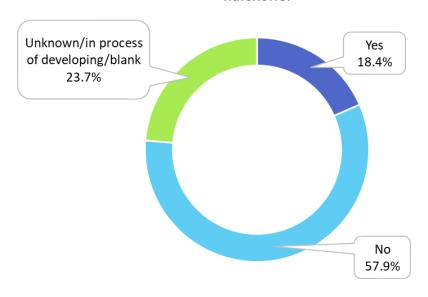


#### NALOXONE PRESCRIBING

Naloxone prescribing appears to be another area with several gaps. Regarding having actual protocols in place to prescribe naloxone, 56.4% of respondents said they **did not** have a protocol for this, while 23.1% responded either as unknown, in process of developing, or left their response blank. Prescribing naloxone can be an important first step in increasing patient access to naloxone within clinical settings, especially when direct dispensing is not financially or logistically feasible. In addition, clinical decision support for naloxone prescribing is needed as it provides a mechanism for prompting clinicians, generally through the existing electronic health records (EHR) system, to prescribe naloxone as part of the clinical visit. Only 23.1% of hospital respondents answered "yes" to having clinical decision support for naloxone prescribing incorporated into their EHR.

Figure 6.

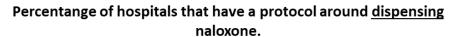
## Percentage of hospitals that have a protocol around <u>prescribing</u> naloxone.

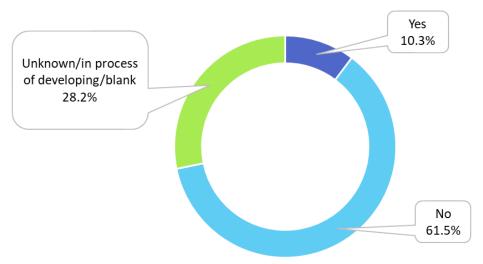


#### NALOXONE DISPENSING

While naloxone prescribing has been growing in popularity, relying solely on the practice of prescribing is an imperfect overdose prevention strategy as it does not always result in the patient receiving a kit in hand for take-home purposes. Naloxone prescribing relies on insurance billing and the motivation of individual patients to pick up the prescription from a pharmacy. Research shows naloxone prescription fill rates can be as low as <1%. 62 Results from a local Chicago study on naloxone prescribing within a hospital ED setting showed that only 18.2% of naloxone prescriptions resulted in patients obtaining the naloxone from the pharmacy. 63 The gold standard for naloxone access is direct distribution of the medication to patients at bedside so they can take it home when discharged from the hospital. Only 10.3% reported having a protocol that supported naloxone dispensing while 61.5% did not, and 28.2% either did not respond altogether or responded as unknown or in the process of developing. In terms of actual naloxone distributed to patients in the ED, only 7.7% reported actively dispensing directly to patients from the ED.

Figure 7.





*Medication for Opioid Use Disorder (MOUD) Access.* Regarding access to medications for opioid use disorder in the ED, several areas for improvement were identified beginning with prescriber capacity, to existing protocol, to services rendered.

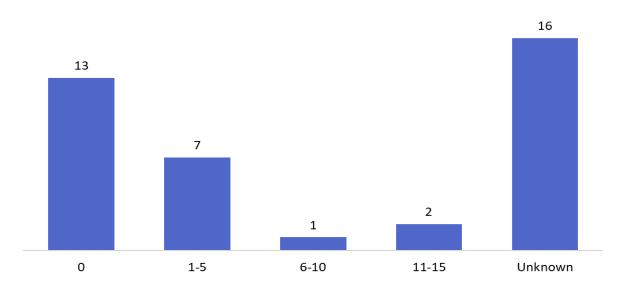
#### PRESCRIBER CAPACITY

Hospital capacity assessment respondents were asked a few questions about prescriber capacity including the number of providers that can prescribe a controlled substance in the ED. Medical personnel who have prescribing authority are eligible to prescribe buprenorphine after completing the required waiver training, per federal regulations.<sup>64</sup> Of the hospitals that participated in the survey, 7.7% of respondents left their response blank when asked about the number of providers who can prescribe a controlled substance. Another 7.7% identified having only between one and nine providers who could prescribe a controlled substance, 64.1% identified between 10 and 49 prescribers, 17.9% identified between 50 and 150, and 2.6% answered having over 250 providers who could prescribe a controlled substance at the time of the hospital ED capacity assessment. Some of the responses suggest the assessment respondent may have been responding to the total number of providers who can prescribe a controlled substance within a hospital system rather than solely within the ED. Having prescribing level trainees (i.e. medical residents) based in the ED can be another way to increase a hospitals capacity. Of the hospitals surveyed, 48.7% reported having this in place compared to 41% who did not, and another 7.7% who either left their response blank or responded as unknown or in the process of

developing. According to hospital capacity assessment results, the number of providers who had completed the training and obtained a waiver to prescribe buprenorphine in the ED was extremely low. Just under 72% of respondents either left their response blank or reported zero providers while another 17.9% reported having between one and five providers who could prescribe buprenorphine. Roughly 3% reported between six and 10 providers, and only 7.7% reported having between 11 and 15 providers in the ED with a buprenorphine waiver.

Figure 8.

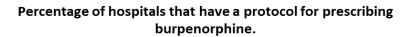
Number of providers in the hospitals with a burprenorphine waiver.

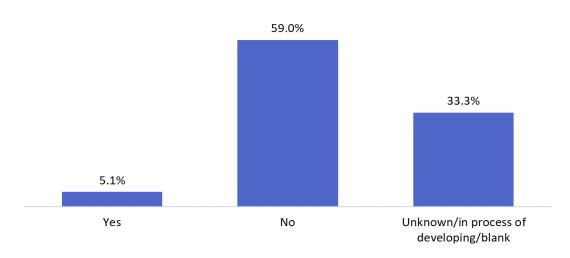


#### **EXISTING PROTOCOL**

A hospital formulary is a list of approved medications medical personnel within a medical institution can use. If a medication is not listed on the hospital formulary, the medication will cost the hospital more if used. Therefore, having a medication on a hospital's formulary may make it easier to promote use of that medication. Surveyed hospitals were asked if buprenorphine was an available medication on their hospital formulary and 53.8% of respondents said yes. Another 15.4% responded no and another 30.8% either left their answer blank, or responded as unknown, or in the process of developing. Hospitals were then asked if they currently had a protocol for prescribing buprenorphine. Only 5.1% responded that they did compared to 59% who responded no, and the remaining 33.3% who responded as either unknown, in the process of developing, or did not answer the question.

Figure 9.





#### SERVICES RENDERED

• Finally, when asked about the number of buprenorphine prescriptions provided in the ED for OUD within the previous year, 2018, 92% of respondents either reported 0, left their response blank or responded that they did not know. Comparatively, only 5% reported between one and five buprenorphine prescriptions given in 2018, and only 3% reported 40.

#### STAKEHOLDER INTERVIEWS

"I can't tell you how many times doctors say or clinicians in general will say, 'I don't want this patient as part of my practice. My whole panel is going to get overloaded. They're going to cause havoc in the waiting room.' All of these sorts of ridiculous scenarios." – FQHC/CHC Provider

A number of findings emerged from the stakeholder interviews. In short, *sufficient access to overdose prevention and treatment services remain a critical gap in our city's landscape and infrastructure during a time in which overdose deaths have never been higher.* Major themes identified included barriers related to access, continuity of care, structural barriers, service user factors and experiences, and COVID-19. Within these major themes, there were 5 most frequently cited barriers which are illustrated through stakeholder interview quotes below. Frequently cited barriers included: Service user readiness, general stigma toward PWUD, lack of

formalized care coordination systems, overall resource scarcity, and co-occurring mental health needs among service users and lack of behavioral health integration.

Service user readiness to change was one of the most frequently cited barriers however was discordant with all the structural and access barriers identified. What was more salient was the understanding that the existing system of care for people at risk of overdose and people with OUD is in fact not "ready" for many service users when they are ready, leaving many to fall through the cracks due to a variety of institutional, practice, and system-level barriers. Similarly, access barriers and readiness beliefs were often shaped by general stigma toward PWUD. Various examples of stigma were provided by both providers and PWUD alike, highlighting the pervasiveness with which discrimination against PWUD thrives across helping systems. The lack of formalized care coordination to aid in transitions of care between institutions was frustrating for providers and often resulted in poor outcomes among patients. Systems that do not talk to each other result in patients getting lost in the shuffle rather than getting the care they need. An overall need for greater resource investment to strengthen existing services was also common. The idea that the resources programs had at their disposal were never enough to meet the need was also expressed. Mention of the presence of co-occurring mental health conditions was common in the context of a contributing factor to substance use that often goes untreated due to poorly designed treatment systems that lack the capacity to treat the whole person.

#### STAKEHOLDER NALOXONE AND MOUD PROVISION

• Limited Emergency Department Naloxone Access Points. Out of 19 programs interviewed, harm reduction programs and opioid treatment programs (OTPs) were the most likely entities to be distributing naloxone directly to PWUD and people at risk of overdose in the form of a take-home kit, with one primary harm reduction program serving as a centralized backbone for the provision of naloxone supplies. As a result of Governor Pritzker's Executive Order from January of this year, which was intended to increase support to address the overdose crisis, additional funding was provided to increase naloxone access to community residents. Some of this naloxone went to OTPs for the distribution of naloxone directly to service users. Earlier this year, IDHS/SUPR, conducted a survey of local OTPs to assess overdose prevention service capacity via naloxone distribution. Results from that survey demonstrate that only 34% of the 50 OTPs surveyed reported already distributing naloxone to patients prior to these recent investments and prior to the onset of COVID-19. In addition, the Federally Qualified Health Centers (FQHCs) and Community Health Centers (CHCs) who were interviewed all reported prescribing naloxone while four of the five reported also providing direct

distribution of take-home kits when prescribing was a barrier. Only one of the seven hospitals IPHI interviewed reported distributing naloxone directly to patients from the ED. Two hospitals reported prescribing while one of the two reported that their hospital was in the process of piloting a direct distribution program out of the ED as well as in outpatient settings. The remaining four hospitals reported no naloxone access point from the ED.

• Delayed Medication for Opioid Use Disorder Initiation Across All Providers. Out of seven hospitals interviewed, three were initiating buprenorphine treatment within the ED, however, two of the three programs had only recently begun providing this service. One additional hospital reported having a doctor on staff who could prescribe. Unfortunately, the practice was not widespread or standardized among other physicians. Finally, the three remaining hospitals reported that their EDs were not initiating buprenorphine treatment from the ED at this time. Out of nine community-based treatment providers interviewed, a wide range of medication (namely methadone and buprenorphine) wait times were reported ranging from one day to one week. Only two out of nine community-based treatment providers reported consistently getting service users MOUD either the same day or next day.

#### EMERGING THEMES AND ILLUSTRATIVE QUOTES

"The need to be abstinent. It's complicated for people. So you're struggling with something that's a habit-based behavior like any of us might struggle with exercise or eating habits or things like that and most people don't change in absolutes and yet in most of our treatment system that's exactly what we expect, is that people walk in the first day and that they change in absolutes. And worse, we punish folks for having slips in that absoluteness. Right, we kick people out of treatment for exhibiting symptoms of their disease, and I can't think of any other health condition where we do that." — Harm Reduction Provider

A variety of themes broadly focused on barriers were also identified. Key findings related to one of the following major themes:

- 1) access barriers,
- 2) continuity of care barriers,
- 3) structural barriers,
- 4) service user factors and experiences, and

5) COVID-19 pandemic-related barriers.

Each major theme is further defined by subthemes and specific examples that are highlighted below. Moreover, the 5 most frequently cited barriers that were identified in roughly half of all the interviews are highlighted below via illustrative quotes. Each of these issues was described as a barrier to service engagement.

1. Access Barriers. Barriers of access were the largest category and can be better understood through a series of sub-themes including barriers of MOUD availability, high threshold service model barriers for MOUD, stigma, and limited naloxone access.

"The challenges for us have always been the strict requirement, like if they need an ID. Sometimes we will make those exceptions but then when we get audited then they will point that one out. 'Why didn't you have an ID?' And sometimes when we admit them, the patients say 'I will get it right after' and then they never do. Just like the state requirements - having an ID, needing a physical prior to admission, lab work. Due to COVID-19, no one wanted to see patients. And the requirement is that it has to be an in-person it can't be like a telehealth or anything like that, it has to be in person." — OTP Provider

#### MEDICATION FOR OPIOID USE DISORDER AVAILABILITY-RELATED ACCESS BARRIERS

Availability-related barriers included examples such as limited prescriber availability which greatly limited MOUD initiation, treatment availability for uninsured individuals, and waitlists for treatment programs or residential facilities. Distance to a treatment facility or pharmacy was another common access barrier as were financial limitations. Several stakeholders talked about the inherent challenges to accessing treatment when the service user or client either did not have insurance at all or did not have the proper kind of insurance to provide appropriate coverage. Without insurance coverage, individuals generally cannot cover the cost of treatment on their own. Relatedly, some stakeholders raised the issue of simply having fewer options if someone was uninsured. Limited dosing and clinic hours were also raised. This was true for methadone clinics, who often begin services early in the morning, close early in the afternoon, and have limited weekend hours. Limited clinic hours were also discussed in the context of limited prescriber availability if for example, individuals could only gain access to medication after seeing a prescriber and that prescriber was only scheduled to work at the program a couple days each week. Related to this is the issue of insufficient numbers of prescribers who are

waivered to prescribe buprenorphine across settings, which then limits how many medical providers are available in any one institution to provide lifesaving medication.

# HIGH THRESHOLD SERVICE MODEL BARRIERS FOR MEDICATION FOR OPIOID USE DISORDER

In the social service field, the terms "high threshold" and "low threshold" are often used to denote how high or low barrier the point of entry to services is.<sup>67</sup> High threshold service model barriers for MOUD included things like technology and travel requirements that limited access for those with limitations to those items. For example, while telehealth in many ways has been a lifesaver for many during the pandemic, access to treatment for OUD has remained highly inaccessible for anyone without a reliable phone or computer. Additional treatment system requirements included things like proof of identification, which is a known barrier for people experiencing housing insecurity and homelessness. Counseling requirements were another major issue as providers and programs often require counseling to initiate treatment and/or continue treatment. Urine drug screens were sometimes raised as a barrier to treatment entry. For example, if a person seeking MOUD treatment tests negative for opioids when drug screened during intake, they are generally denied treatment access. Some PWUD have experienced treatment denial even though they were actively using at the time of intake. Research is needed to better understand the reliability of some drug testing technologies and the potential vulnerabilities within the illicit market. An over-reliance on abstinence as a precondition for help was also raised. Drug testing via urine screens is a widespread screening practice in MOUD treatment and has often been used punitively to restrict patients who continue to use illicitly. Having reliable transportation was commonly mentioned as was the requirement among methadone clinics that service users visit daily to get dosed.

Furthermore, many stakeholders spoke about individual will and individual desire as a critical factor to engage in treatment services. This was described as a "readiness to change". This emphasis on individual readiness sometimes conflicted with structural-level barriers presented by stakeholders. While there is certainly truth in the idea that individual will and desire are essential components of behavior change, readiness to change was often described in the context of an individual's personal failings. An alternative treatment and prevention system that

is respectful, compassionate, responsive to people's needs, and supportive of incremental change could substantially impact an individual's motivation to seek care.

# Service User Readiness to Engage in Treatment Services: Illustrative Quotes

"There is a lot of help out here. Not everybody wants help. Heroin addiction is problematic only when it's problematic. And a lot of times it's not problematic to individuals." - *OTP Provider* 

[When asked about barriers to ED initiation of buprenorphine- the hospital did not at the time of the interview provide this service] "I think the biggest thing would be patient agreement....I think generally our opioid overdose population, a large portion of them are you know, extraordinarily pleasant and lovely when they wake up but they aren't all that interested in seeking treatment acutely." — *Hospital Provider* 

"Retaining people is a challenge because of readiness to change issues....the only barrier is a person's willingness to follow up." – *OTP Provider* 

#### STIGMA FROM PROVIDERS

Stigma on the part of healthcare and treatment providers is pervasive and well documented in the literature. 68 Stigma was a major and recurring theme among stakeholders that included a general resistance toward working with PWUD and toward MOUD. Providers were described as having regressive attitudes toward PWUD and OUD that influenced their interaction with service users. Examples of both experienced and perceived stigma were shared by stakeholders. This included beliefs around PWUD being undesirable, dishonest, and/or unruly people. It included negative beliefs around MOUD such as the idea that medication for people with OUD is enabling drug use and simply substituting one drug for another or that medication alone is ineffective despite the evidence. Several stakeholders spoke to their experience with drug problems being treated as a choice rather than as a health condition. If substance use problems are a condition, there is room for empathy and the possibility of rehabilitation. However, if it's a choice, it becomes acceptable to blame individuals for poor decision-making. The view that PWUD are on the whole undesirable or that their condition is the result of some kind of moral failing greatly impacts the quality of care received by service users. Service users described feeling looked down upon by providers as well as a general fear of discrimination by helping professionals which was often described as a reason to delay or avoid care altogether. Stakeholders described inadequate treatment for PWUD and the use of punitive practices versus employment of a

trauma-informed approach to care. Stigma was also discussed in regards to limited provider competency which was described by one stakeholder as "extreme ignorance", and by other stakeholders as an overall lack of understanding of the issues impacting PWUD, of addiction care, and of best practices.

# **General Stigma Toward PWUD: Illustrative Quotes**

"In terms of community-based addiction providers, there's still a lot of outpatient programs that tell our patients regularly that they're getting high because they're taking medication or they're falling asleep in group or just blatantly, I mean we see less of this but they say they can't be taking the medication." – FQHC/CHC Provider

"Then I think that there's a lot of stigma through ERs well not just ERs but healthcare overall.

A lot of times when patients are coming in to ask for help with you know going through withdrawals or you know just wanting to be stabilized on medication, they get labeled as you know 'drug-seeking' or they have this stigma of people not really wanting to be bothered with helping them kind of navigate the system. So I feel like a lot of people get kind of defeated before they can even get started." – *Hospital Provider* 

"I have had a lot of bad experiences with doctors especially once they know that I'm a user you know, and how they treat you especially if you're coming through the emergency room on an overdose. Once they find out that's the reason you're there they literally ignore you, don't want to attend to you or you hear them talking you know, under their breath about you or in the next room. You know, saying nasty things you know? And I look at it this way. If you're a healthcare worker, you've given up a certain part of your life to helping people. That is what you do. That is your function in life is to help others. And I don't care if it's cancer or it's an overdose. That should never differ. You should treat that person the same, one way or the other. Not as a 'drug addict that ain't got any kind of direction in their life' and they're a piece of shit. You know? You don't look at people like that. You don't know who those people are when they come in through that door and they're dead and you're trying to save their life. I mean how do you know who that person is? That person might be the next president or might be the next inventor you know? We're not dumb people just cause we're drug addicts."

— Service User

#### LIMITED NALOXONE ACCESS

Among the stakeholders interviewed, the setting with the least access to naloxone for patients was hospital EDs. However, hospital-based providers and non-hospital-based providers spoke about ongoing barriers to naloxone access due to cost and regulatory challenges, limitations due to prescribing, and limited opportunities for secondary exchange. The cost of naloxone continues to be an issue. The issue is exacerbated when a patient is uninsured, or the program is interested

in direct dispensing and does not have an outpatient pharmacy. Even in the case of prescribing, patients are less likely to make a special trip to pick up the medication at the pharmacy as aforementioned.<sup>69</sup> Providers who are doing direct dispensing are often dependent on unsustainable funding models such as grants and donations. Limitations of strictly prescribing naloxone also include that prescription methods restrict the quantity of naloxone a patient can receive at any one time. In comparison, direct dispensing may allow for secondary exchange<sup>70</sup>, the practice of providing extra supplies with the understanding that they will be shared with others in a person's network to prevent rationing or running out, a best practice within harm reduction service models.

2. Continuity of Care Barriers. Barriers related to formalized linkage systems that seek to ensure continuity of care, was another salient theme highlighted by stakeholders.

"In terms of recovery homes, if you think of housing as a huge part of someone's recovery, recovery homes therefore are part of the continuum of care. We still have homes...just yesterday I was working with a patient who just finished residential treatment at [treatment program], is still there, does not have funding and is in need of a SUPR licensed recovery home bed, is doing really great and really wants to be in a sober, supportive environment but can't find a home with a bed that will take her with buprenorphine. She's been offered 3 beds now but they've all said she has to stop buprenorphine." – FQHC/CHC Provider

#### ABSENCE OF ROBUST CARE COORDINATION SYSTEMS

This was described as an overall lack of discharge planning and follow up, an over-reliance on referrals rather than warm hand-offs, and informal partnerships when some level of cross-sector collaboration was identified. Some providers talked about the challenges of receiving a patient with complicated and/or multiple needs without any coordination or basic information about the patient such as medical records, specialty service needs, ID or insurance information. Others voiced the challenges of getting a client from point A to point B and the difference it made when clients would receive transportation support and/or when the linkage between institutions was clear and seamless. Partnerships that did exist were often described as informal arrangements that sometimes depended upon a relationship between individuals rather than an institutional-

level commitment toward collaboration. Several providers were unaware of harm reduction services in their area or what such programs offered.

# <u>Lack of Formalized Care Coordination Systems and Discharge Planning Across the Board:</u> Illustrative Quotes

"And follow up is just tough. Our area has a really hard time with follow up and I don't know, maybe more case workers helping people kind of navigate all of it would be very helpful. You know whenever I try to go do my own medical things for myself or family its overwhelming and so um I think that for people with an addiction number 1, and you know of course with those who haven't had the same access to education and technology, I think it's almost paralyzing. So I think finding advocates for them in some sense, whatever you want to call them, to help them navigate all that and connect them to the right places. I think that's really missing." — *Hospital Provider* 

"We're still super siloed. There is not a system of care regionally. It's still clinic and hospital and OTP and IOP and OP and recovery home and jail." – FQHC/CHC Provider

"I think if more facilities had more care coordinators within them....if more hospitals and community-based programs had care coordinators to assist with the counselors and things like that, I think we could really help these patients to really navigate this system a whole lot better. Because that takes a lot of dedicated time to make sure that someone is you know, able to get to their appointments and that they made it there, that they have the transportation that they need, they have the things set up for them at home. You know, it would help a lot with someone who is trying to do the counseling. It would help all of us work together as a team if we had those additional persons or people in these different facilities that can help everyone when navigating the system a little bit better....We have 1-2 counselors here and there and you know they're underpaid, they have a huge clientele, they don't have a lot of time to do a lot of this, the stuff that care coordinators could do."

# Hospital Provider

3. Structural Barriers. Structural barriers were often identified by interviewees. These barriers included social equity issues like housing access, food insecurity, unemployment, and criminalization of substance use, which interviewees described as major barriers to prevention and treatment system engagement. Additionally, system-level barriers due to limited health system integration, and regulatory and financial barriers were referenced as further impediments to resource access.

"You know we've got a housing crisis. I think that's so big and that really affects people's ability to be retained in care and show up for appointments. There's a lot of barriers based off of broader social concerns that really have nothing to do with someone's motivation for treatment but really impact their ability to access it. And that's especially disheartening for me as I watch folks go through a 28 day and then a 3-5 month recovery home and then be discharged back to the streets. That story is way too common. And the supports that are in place in these programs to secure discharge plans that will support their path to health are very limited." — FQHC/CHC Provider

#### SOCIAL AND STRUCTURAL INEQUITY

This included broad resource scarcity regarding available services as well as population needs including things like housing access, poverty and unemployment, food insecurity, and criminalization of substance use. Stakeholders often described the needs of the community and people they were serving as much greater than their organization's capacity to meet that need. A lack of permanent infrastructure to support essential services was raised in the context of programs being dependent on limited grant funding, insufficient staffing capacity, and the limitations of some existing services like recovery homes that are not always responsive to the needs of people with OUD (i.e. not providing housing to people on MOUD, essentially making people choose between housing and MOUD). Social and structural inequity was discussed as barriers that prevent people from participating fully in the treatment system and/or from gaining access altogether.

# Resource Scarcity as a General Limitation to Service Providers Providing Care and Service Users Engaging in Care: Illustrative Quotes

"....generally and especially now there's no room in any of the programs. And with COVID that's been a whole other thing. You know because a lot of places just weren't taking people. So unfortunately a lot of times they [service users] are going to shelters and you know that generally is just back onto the street....In the best of times it's difficult to find space for people, you know our community is, most are not going to have private pay insurance. So you're looking at, a tough sell in trying to get them in these programs when beds are few and far between. You know having been in the middle of the opioid crisis before this and now with COVID on top of it it's next to impossible." — *Hospital Provider* 

"I do think we do have a lack of resources in our area. I think that sometimes they [resources] come in and they seem like maybe they don't last." — Hospital Provider

"Resources, resources, resources. They [community providers] are underfunded, overwhelmed, and I'll tell you COVID really struck them hard....they [the city] need to fund these community providers to keep them solvent, to keep them up and running so that they don't overwhelm our ERs or just hanging out on the street and becoming worse. So we really need to deal with that and it's an initiative that I have been advocating for a while since COVID with the disparities being totally exposed it's really imperative that they put resources in the community." — *Hospital Provider* 

#### LIMITED HEALTH SYSTEM INTEGRATION

Limited health system integration was expressed as a common explanation for gaps in service between behavioral health and primary healthcare as well as between mental health and substance use service systems. Some stakeholders spoke to a need for a whole health approach that addressed the needs of the person seeking services in a comprehensive way. Some interviewees stressed the need for increased integration to address the disjointed connection between substance use and mental health within the behavioral health system. One example of how this came up in interviews included issues of service users experiencing discrimination or even being refused care in a substance use treatment program because they had a diagnosed mental health condition. To a lesser extent, integrated care was also discussed as a way of opening the door to other needs. For example, one provider talked about how treating SUD was sometimes a vehicle for beginning to address primary care needs as well. Another example that was shared included hospitals discharging patients and attempting to connect them to a community-based program without understanding how the program operated and what patients would need in order to complete an intake appointment. Lack of treatment system integration undergirds a variety of challenges that arise from the siloed structure of the treatment system and contributes to the lack of coordinated mechanisms to support continuity of care.

# Co-occurring Mental Health Needs Among Service Users and Lack of Behavioral Health Integration: Illustrative Quotes

"There are a lot of patients that self-medicate and that's a huge factor. They are kind of this dual diagnosis. They have behavioral health issues and the only way they can take care of them are by you know using some type of opioid or cocaine or alcohol to self-medicate. So I think that part of it is addressing behavioral health. I think there's a lack of that just everywhere." – *Hospital Provider* 

"....I had a bad experience with treatment programs. When you get into the programs they expect it to be a quick fix. And then there's a lot of people, like mental health, such as myself, that the programs don't even touch those bases so if you don't treat the whole problem how can you ever get well, ya know? There are so many people suffering from using because of mental issues and they don't help you at all with those kind of things." – *Service User* 

"Oh I've had clients go for treatment and when they were being interviewed to get in, one client in particular told them, 'well I'm schizophrenic and I'm taking medication for that.' The guy stopped the interview right there. Told him, 'well I can't help you cause of the medications you're on, so this interview's over and you got to leave my office.' So the guy left his office, sat in the waiting room waiting for his wife. They told him, 'oh you can't sit here either.' They made him go outside and the guy literally followed him outside and said, 'you can't stand in front of the building.' And I was like, 'what'? Why are we sending people to these agencies and they're turning them away like this? Ya know, what's the purpose?" – Harm Reduction Provider

#### REGULATORY AND FINANCIAL BARRIERS

Examples of regulatory and financial barriers included federal DEA regulations that limit MOUD access overall, waiver barriers for buprenorphine prescribing, and naloxone purchasing and dispensing. Some providers talked about the reticence of colleagues to become buprenorphine prescribers due to fear of DEA involvement. Several providers discussed the challenges of working within a heavily regulated field. The specifics varied between type of treatment provider. The X waiver requirement for buprenorphine create barriers in terms of staff time to get trained and the cost associated with obtaining the waiver. Buprenorphine prescribers are also limited by the number of patients they can treat and the number of prescriptions they can provide. Methadone treatment involved other barriers such as the strict requirements for getting in the door (i.e. proof of ID, ability to pay or proof of insurance) and the requirements around supervision of medication intake (i.e. daily visits to methadone clinic) that can be a logistical barrier for many service users. While restrictions have been loosened in many ways in

response to COVID-19, unlike with buprenorphine, methadone clients are still required to have an in-person physical before initiating treatment.<sup>71</sup> Not to mention, methadone remains the only FDA-approved medication for OUD that by law, is relegated to a system entirely separate from primary care.<sup>72</sup> Naloxone purchasing barriers had to do with a number of issues. Quite simply the high cost of the medication limits direct dispensing capacity among service providers. Statewide standing orders or even institution-specific pharmaceutical contracts often place limits on the formulations of naloxone that can be accessed (i.e. cheaper formulations vs more expensive formulations).<sup>73</sup> State administrative codes may also call into question medication dispensing vs. medication administration rights within hospital ED settings, as well as state pharmacy regulations surrounding the proper storage and record-keeping of medications dispensed.<sup>74</sup>

4. Service User Factors and Experiences. Service user factors and experiences comprised internalized stigma, descriptions of a low self-concept, and misinformation factors shared by stakeholders. Co-occurring mental health needs were also commonly raised throughout the interviews. These factors do influence a person's motivation and desire to seek treatment, however, given the lack of power most service users have over the treatment system, these factors should be understood as a consequence of marginalization rather than a cause of it.

"The fact that I can't control myself, that I'm such a dope addict, and that I keep doing something that I know is wrong to society. It's because society looks so down on it like, 'oh you're such a scumbag if you do this.' You know? And I feel like when I walk in there and tell them yea that's what I keep doing...I'm not smoking weed, I'm not doing cocaine. No, I'm doing the worst shit of all, I'm doing heroin. You know what I mean? I feel like people are looking at me like, 'you dirty dump dog', you know? And that's just how you feel. I've had conversations with doctors that you know, they just shake their head and say what you're doing is gonna kill you. And doctors they say things like that." — Service User

## INTERNALIZED STIGMA, SELF-CONCEPT, AND MISINFORMATION FACTORS

This section was important to highlight due to the shame often internalized by PWUD and the myths around MOUD perpetuated by society that service users often adopt. Negative perceptions and myths contribute to internalized or self-stigma<sup>75</sup> that can significantly contribute to delays or avoidance of service engagement. Some service users talked about how terrible it makes them feel to have to talk to service providers about their problems because of their own

guilt and shame, and how they perceived themselves to be viewed and judged by those around them. Some service users voiced self-blame for relapsing following treatment or detox experiences. Stakeholders also repeated common myths about MOUD they had internalized, such as the idea that MOUD is simply substituting one drug for another, that MOUD damages one's body, or that people shouldn't be on medication for very long. Given the misinformation and stigma perpetuated by health providers and the general public, it is unsurprising that these messages are internalized by PWUD. Such dynamics are not uncommon among groups experiencing marginalization and they can contribute to profound psychological hardship.<sup>76</sup>

# CO-OCCURRING MENTAL HEALTH NEEDS

This was a common theme that came up in several interviews as a contributing factor to substance use and substance misuse. Nearly all of the service users interviewed raised their own mental health needs as a contributing factor to their use, and/or as a significant need they felt substance use treatment should address and often did not. Some service users also shared about the trauma of surviving an overdose and/or the trauma of losing a loved one to an overdose.

5. COVID-19 Pandemic-related Barriers. COVID-19 barriers centered on changes in service availability overall due to physical distancing safety regulations and communication barriers due to limited technology access on the part of service users.

"During COVID it's definitely become more difficult to access MAT services, because, I don't know what other FQHCs are doing but I think guidelines have been quite clear that we should not be allowing walk-ins or not advertising for walk-ins so in order to begin or maintain a [buprenorphine] prescription right now it does feel like you need to have a cell phone and tons of our patients don't. So we try and get as creative as we can but in order to set up an appointment you need to either, have a conversation with someone over the phone where you can go through COVID screening and if you're negative you go to this side of the clinic, if you're positive you go to another side. Either side you get buprenorphine but you have to be able to provide that screening before an appointment can be made and that's been a big frustration for me because that is very difficult for patients without cell phones to do that screening. So that's been a significant barrier to care that's specific to these times." — FQHC/CHC Provider

#### COVID-19-SPECIFIC BARRIERS

An overall loss of access to services was the main challenge identified related to the pandemic. Specifically, the loss of walk-in access that some clinics and programs employed prior to the outbreak, the loss of in-person provider visits that have resulted in delayed care, and increased wait times for receiving MOUD. In addition, some providers spoke about the loss of recovery-based support groups and having to transition online which left many service users without access to those services. A few providers also raised feelings of burnout from working in crisis for such a long time and without a clear end in sight. It is unfortunately unsurprising that a population experiencing severe marginalization during "normal times" would become further marginalized amid a global pandemic. Therefore, given the unique challenges presented by COVID-19, protocols that restrict service access during this time must be reviewed and safer alternatives that broaden access extensively employed.

## SECTION 6: UNDERSTANDING THE DATA

While the data varies by method (i.e. quantitative vs. qualitative) and stakeholder focus (i.e. hospital-specific vs. broader community-level), the purpose that drove the data collection was similar —to assess capacity and identify and understand barriers. The hospital capacity assessment findings along with the stakeholder interviews provide an even clearer picture of the gaps across substance use care. Hospitals are unprepared to respond adequately to the overdose crisis and community providers are unable to meet the needs on their own. Hospital systems and hospital-based providers are at the beginning stages of incorporating addiction care into the broader healthcare framework. Additionally, medical and social service systems largely operate separately. This leads to a fragmented and disjointed approach to addiction care rather than a coordinated, robust, and comprehensive approach in which transitions of care are understood, and opportunities to connect people to different levels of care dependent upon their needs is possible. The hospital capacity assessment and interview findings complement one another and point to geographic-specific needs within the city.

It is well documented that Chicago's West and South Side communities experience a very unequal city in many ways. The social and structural inequities that many West and South Side Chicagoans face create the conditions for health disparities, including SUD and overdose. The issue is not that racial minorities are using more drugs than their white counterparts. Rather, the overdose prevention, treatment and response services in the communities hardest hit by the overdose crisis in our city – the West and South Side – are insufficient. Beyond the prevention and treatment landscape, members of West and South Side communities struggling with substance use also face serious structural harms that limit their ability to successfully engage in

prevention and treatment services such as poverty, lack of affordable housing, food and healthcare deserts, and so on. Add to that a constantly changing illicit drug market that is becoming increasingly poisoned by fentanyl analogs and novel synthetic opioids that even seasoned users do not have the tolerance for, not to mention a deadly global pandemic. Given this context and data from the landscape analysis, the scale at which people are dying from drug overdoses should not shock us. Rather, it should spur us to swift, collective action.

# Understanding the barriers makes clear the gaps in overdose prevention, treatment and response and the need for the following changes:

- 1. Increased resource allocation for new services and existing services as well as the adoption of low-threshold service models and sustained policy change.
- 2. Capacity development by way of training, peer workforce development, and stigma reduction.
- 3. Structural advancements to decrease social inequity particularly around housing and criminalization.
- 4. Increased system integration that strengthen transitions of care.
- 5. Upstream regulatory changes to increase MOUD and naloxone access.

## **SECTION 7: RECOMMENDATIONS**

# RESOURCE ALLOCATION FOR NEW AND EXISTING SERVICES, ADOPTION OF LOW-THRESHOLD MODELS, AND SUSTAINED POLICY CHANGE.

This recommendation is not new, yet it cannot be overstated. More evidence-based programs and services for SUD, particularly OUD, are simply required to meet the need. For existing programs this means increased funding for community-based providers so they can expand hours of operation and afford a prescriber for more than a couple days a week. Investing in existing treatment infrastructure means adequate funding so that programs can afford to bolster case management services to assist service users with critical needs like transportation, getting a state ID, and addressing primary healthcare needs. One great example of this was the investment made earlier this year because of Governor Pritzker's Executive Order to address the overdose crisis, whereby OTPs received naloxone to distribute directly to their clients. The hope is that this new investment in resource allocation can be sustained over time, becoming part of the city and state's permanent overdose prevention and response strategy.

 FREE, ON DEMAND, AND UNLIMITED NALOXONE AND MOUD. Life-saving medications like MOUD and naloxone must be made widely available, regardless of one's ability to pay, and must include all relevant healthcare entities as well as jail and prison populations. PWUD and their loved ones should have multiple naloxone access points at their disposal that prioritize an unlimited, secondary exchange model of distribution.<sup>78</sup> Access points should be designed with a low-threshold model in mind that limits gatekeeper involvement.<sup>79</sup> All MOUD-based treatment should adopt and adhere to a low-threshold model as well that ensures same-day access to medication and allows for walkins.<sup>80</sup> Programs should be expanded to accommodate evening and weekend hours.

# CAPACITY DEVELOPMENT VIA TRAINING, PEER WORKFORCE DEVELOPMENT, AND STIGMA REDUCTION.

Widespread implementation of evidence-based curriculum on substance use and misuse that addresses stigma is needed across all healthcare sectors - primary care, behavioral health, and pharmacy, in addition to criminal justice and judicial systems, and social services. <sup>81</sup>, <sup>82</sup> Curriculum inclusion should be tied to a program's accreditation and to the licensure of individual providers. Accountability mechanisms should be developed to both prevent and respond to cases of continued discrimination against PWUD, coerced treatment, and failure to utilize evidence-based services (e.g. drug courts sending people to non-evidence-based programs). Investing in the peer recovery workforce is another important way to build capacity and reduce stigma. Peers are workers with lived experience who take on a "helper" role typically within a direct service setting, and are a great way to build trust and increase comfort among service users. <sup>83</sup> Peer workers support clients and relieve capacity barriers on other providers. Research shows that service providers who have had little to no exposure to PWUD are more likely to be governed by fear and assumptions. <sup>84</sup> Incorporating peer workers into the service environment benefits service users by helping advocate for patient rights and needs while also helping to educate their provider colleagues along the way. <sup>85</sup>

INTEGRATE HARM REDUCTION AND TRAUMA-INFORMED CARE INTO RECOVERY AND TREATMENT FRAMEWORKS. While substance use treatment is slowly beginning to adopt aspects of the harm reduction approach, greater adoption is needed. Recovery must be client-centered and client-defined, rather than restricted to narrow definitions of abstinence-only metrics that fail to recognize the needs, realities, and preferences of service users. Many people with a SUD also have trauma histories yet substance use treatment often lacks a trauma-informed approach. See Like all other health conditions, SUD treatment must be approached with the goal of reducing harm and optimizing wellbeing. Shifting from our current one size fits all model to a more holistic model that embraces incremental change will mirror how other health conditions are treated and more importantly will be more effective and humane. Training on harm reduction and trauma-informed care should be required for all providers working in the substance use field. In addition, patient outcomes should be reconfigured to support incremental change. As a shining example, one of the stakeholders interviewed for the landscape

analysis, spoke about how their program measured success by the following three metrics: 1) length of time retained in treatment, 2) whether there was a decrease in overall overdose incidents, and 3) whether there had been progress made on the patient's self-directed goals.

#### DECREASE SOCIAL INEQUITY - HOUSING AND CRIMINALIZATION.

People with a SUD are marginalized because their condition, which relies on the consumption of illicit substances, is illegal. This is not the case with any other chronic health condition. Until people with SUDs can be treated as people with a chronic health condition rather than as people engaging in criminal behavior, they will continue to be discriminated against across all major systems from healthcare to housing. Movements toward broad decriminalization have been steadily gaining momentum across the country. For example, the Portugal model has demonstrated the effectiveness of treating substance use as a public health rather than a criminal justice issue. Having decriminalized use and possession in 2001, the country has seen dramatic decreases in overdose fatalities and HIV infections.<sup>87</sup>

• SUPPORT DRUG DEFELONIZATION IN ILLINOIS. As a move toward broader decriminalization reform, local advocates have been working to pass a state law that reduces penalties for possession of small amounts of illicit substances from a felony to a misdemeanor.<sup>88</sup> Such a move would be a great step forward toward reducing criminal penalties for an issue that is a matter of health rather than public safety.

Criminalization of substance use is also one of the biggest barriers to housing that PWUD experience. Increasing the number of recovery homes<sup>89</sup> and housing first programs<sup>90</sup> for people with SUDs is critical.

• REFORMING RECOVERY HOMES TO SUPPORT MOUD. State Opioid Response (SOR) grants should fund the development of new recovery homes that support MOUD. 91

Additionally, capacity development among existing recovery homes that are publicly funded should be prioritized and should include work plans that move recovery homes toward best practice models by changing policies and practices. Given limited resources and the escalating overdose epidemic, public dollars that currently fund recovery homes should move toward requiring funded entities to accept people who are taking MOUD. Grievance mechanisms should be developed to document discrimination cases and provide a venue for the promotion of consumer rights. 92

When a recovery home is not an appropriate level of care for someone because of continued illicit or chaotic use, expedited housing first programs should be available to meet the housing needs of those individuals. Increased funding for housing first programs is also needed. As one of the stakeholders interviewed articulated, "housing is part of the continuum of care", and so it must be treated.

#### INCREASE SYSTEM INTEGRATION TO STRENGTHEN TRANSITIONS OF CARE.

While there are a number of integrated care models<sup>93</sup>, what is widely accepted are the benefits and improved outcomes of aligning mental health and substance use care with primary care.<sup>94</sup>,<sup>95</sup> When systems operate separately, they lack the expertise needed to adequately meet the needs of the whole person. Integrated care models have been shown to increase access to services, reduce costs, and improve the quality of care received by patients.<sup>96</sup> Programs and services that follow comprehensive, integrated models should be incentivized to increase greater widescale adoption. Support for co-located services, formalized collaborative partnerships between agencies, and actual integration of services into a single system of care are all needed. Working with local hospitals and community-based providers to move toward a more integrated system of care would increase capacity by building on the strengths of existing services and would provide a better healthcare experience for service users as well as providers.

### REGULATORY CHANGES TO INCREASE MOUD AND NALOXONE ACCESS.

While many barriers are due to prohibitive federal regulations that are beyond the scope of state-level reforms, it remains important to highlight the policy barriers that impede access on a national level and emphasize the significance of states advocating for federal-level reforms such as those mentioned here.

- MAKE COVID-19 MOUD CHANGES PERMANENT. The recent regulatory changes that
  loosened restrictions around MOUD because of COVID-19, have been a major step
  forward in increasing access to care. These changes allowed for longer take-homes as
  well as the use of telehealth to initiate buprenorphine treatment and for maintenance of
  methadone.<sup>97</sup> Chicago public health advocates and healthcare providers should advocate
  that these changes which are currently temporary, be made permanent.
- ELIMINATE X WAIVER REQUIREMENTS. In step with what other North American and European countries have done, policy change is needed to make buprenorphine prescribing by providers and medication access on the part of consumers widely available. 98 Elimination of the X waiver requirement for buprenorphine prescribing and the limits on the number of buprenorphine patients a prescriber can be treating at one time is needed to improve access and reduce overdose mortality. 99
- END METHADONE REGULATIONS THAT PREVENT ACCESS IN PRIMARY CARE SETTINGS. Advocacy efforts should include loosening federal regulations that inhibit methadone access as well by moving to eliminate methadone restrictions in primary care settings<sup>100</sup>. Research from countries that have integrated methadone into primary care and pharmacy settings demonstrates that when restrictions are minimized, treatment participation increases.<sup>101</sup>,<sup>102</sup>

- OVER-THE-COUNTER (OTC) NALOXONE. Naloxone's status as a prescription drug should be modified so that the medication can be approved as an OTC medication. The Food and Drug Administration (FDA) along with Congress has the power to do this. Such a move would drive down the cost of naloxone and increase accessibility.
- *MEDICAID BILLING.* States must work with their local Medicaid programs to address reimbursement barriers that impact billing for evidence-based interventions such as overdose education and naloxone distribution across hospital settings.<sup>105</sup>

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# **SECTION 9: APPENDICES**

#### APPENDIX A. HOSPITAL EMERGENCY DEPARTMENT INTERVIEW GUIDE

## Background

- Can you state your name, your title, and the name of your hospital?
- Can you state how long you have been in your role?
- Can you state what Chicago communities or locations you work in?
- And can you say briefly what you do on a day-to-day basis?
- What is your relationship to the emergency department?

- What services for persons with OUD does your ED currently provide?
  - Examples might include initiating or prescribing buprenorphine treatment for opioid use disorder; dispensing or prescribing naloxone; offering a referral or "warm handoff" to an addiction treatment provider.
- Can you explain what would typically happen when someone comes in after experiencing an opioid overdose? (What kinds of services are they offered, linkages, etc.)
  - o What is the best-case scenario with regard to services received?
  - o What is the worst-case scenario with regard to services received?
- Does your ED routinely give naloxone/Narcan- either through a prescription or by dispensing a kit?
  - o If yes Among patients who have been assessed to be at risk of overdose, what percent of the time would you say the ED is distributing naloxone either directly or via prescription?
  - o *If they distribute naloxone* What is the process for determining whether a patient receives naloxone/Narcan or not?
  - o What barriers stand in the way of giving people with OUD naloxone/Narcan?
- Does your ED routinely initiate buprenorphine- either in the ED or via prescription with instructions on how to take it?
  - o *If yes* Among patients who have been assessed to be at risk of overdose, what percent of the time would you say the ED is initiating buprenorphine?
  - o *If they initiate bup tx* What is the process for determining whether a patient receives a buprenorphine induction or not?
  - o What barriers stand in the way of initiating buprenorphine treatment in the ED?
- Does your ED have established relationships with community-based addiction treatment providers? If so, describe that relationship and partnership.
  - o What barriers stand in the way of linking people to community-based addiction treatment?
  - o For patients who have been assessed to be at risk of overdose, what percent of the time would you say the ED is connecting patients to community-based medication-assisted treatment services to continue care?

- Does your ED have established relationships with community-based harm reduction service providers such as syringe exchange programs? If so, describe that relationship and partnership.
  - What barriers stand in the way of linking people to community-based harm reduction services?
- What would you say is needed to support greater hospital-to-community partnerships for care coordination?
- Based on your experience, what do you think is needed to adequately meet the needs of people with OUD receiving services in your ED?
- Is there anything else you would like to add about any of the topics we've discussed today?

## APPENDIX B. FQHC/CHC INTERVIEW GUIDE

#### Background

- Can you state your name, your title, and the name of your organization?
- Can you state how long you have been in your role?
- Can you state what Chicago communities or locations you work in?
- And can you say briefly what you do on a day-to-day basis?

- Do you offer medications for opioid use disorder (OUD) treatment? If so, which ones (buprenorphine and/or extended release naltrexone/Vivitrol)?
  - O What is the average time it takes for someone to start treatment from their initial request to receiving medication?
- What barriers stand in the way of getting people timely access to initiation of medication for opioid use disorder?
- What barriers stand in the way of retaining people with OUD in medication-assisted treatment?
- Does your program give people naloxone/Narcan- either through a prescription or an actual naloxone kit?
  - o *If yes* What percent of the time would you say your buprenorphine program is distributing naloxone/Narcan directly to patients?
  - o What barriers stand in the way of giving people with OUD naloxone/Narcan?
- Do you have any existing hospital partnerships specific to addiction treatment for people with OUD? If so, describe that relationship and partnership.
  - How often would you say hospitals are sending patients to you for buprenorphine treatment?
    - Prompt Never? Sometimes? Regularly?
  - What types of barriers have you encountered when trying to partner with hospitals?
- Does your program have established relationships with community-based harm reduction service providers such as syringe exchange programs? If so, describe that relationship and partnership.
  - What barriers stand in the way of linking people to community-based harm reduction services?
- Based on your experience, what do you think is needed to adequately meet the needs of people with OUD seeking services?
- Is there anything else you would like to add about any of the topics we've discussed today?

#### APPENDIX C. OTP INTERVIEW GUIDE

## Background

- Can you state your name, your title, and the name of your organization?
- Can you state how long you have been in your role?
- Can you state what Chicago communities or locations you work in?
- And can you say briefly what you do on a day-to-day basis?

- What is the average time it takes for someone to start treatment from their initial request to receiving medication?
- What barriers stand in the way of starting people with OUD on methadone?
- What barriers stand in the way of keeping people with OUD in methadone treatment?
- Does your program give people naloxone/Narcan- either through a prescription or an actual naloxone kit?
  - o *If yes* What percent of the time would you say your methadone program is distributing naloxone/Narcan directly to clients?
  - o What barriers stand in the way of giving people with OUD naloxone/Narcan?
- Do you have any existing hospital partnerships specific to addiction treatment for people with OUD? If so, describe that relationship and partnership.
  - o How often would you say hospitals are sending patients to you for methadone treatment?
    - Prompt Never? Sometimes? Regularly?
  - What types of barriers have you encountered when trying to partner with hospitals?
- Does your program have established relationships with community-based harm reduction service providers such as syringe exchange programs? If so, describe that relationship and partnership.
  - What barriers stand in the way of linking people to community-based harm reduction services?
- Based on your experience, what do you think is needed to adequately meet the needs of people with OUD seeking services?
- Is there anything else you would like to add about any of the topics we've discussed today?

### APPENDIX D. HARM REDUCTION COMMUNITY PROVIDER INTERVIEW GUIDE

## Background

- Can you state your name, your title, and the name of your organization?
- Can you state how long you have been in your role?
- Can you state what Chicago communities or locations you work in?
- And can you say briefly what you do on a day-to-day basis?

- What services for people who use drugs (PWUD) does your program currently provide?
- What barriers to providing services for PWUD are you currently experiencing?
- Does your program give people naloxone/Narcan?
  - o *If yes* What percent of the time would you say your program is distributing naloxone/Narcan directly to participants?
  - o What barriers stand in the way of giving PWUD naloxone/Narcan?
- Do you have any existing hospital partnerships specific to addiction treatment for PWUD and people with OUD? If so, describe that relationship and partnership.
  - o What types of barriers have you encountered when trying to partner with hospitals?
- Do you have any community-based treatment partnerships specific to supporting PWUD? If so, describe that relationship and partnership.
- What barriers stand in the way of getting PWUD to initiate medication-assisted treatment (MAT)?
- What barriers stand in the way of retaining PWUD in MAT?
- Based on your experience, what do you think is needed to adequately meet the needs of PWUD seeking services?
- Is there anything else you would like to add about any of the topics we've discussed today?

### APPENDIX E. SERVICE USER INTERVIEW GUIDE

I'm going to start with a little bit of background on you

- 1. Do you currently live on the west or south side of Chicago? If not, can you describe what your experience is with the west or south side of the city.
- 2. How long have you been using opioids like heroin? And what is your preferred method of use?
  - a. Probes: injection? Snorting? Smoking? Other?

I'm going to move into some questions about services and treatment.

- 1. What do you think about the harm reduction services that organizations like CRA offer such as safer drug use information, new paraphernalia supplies, naloxone/Narcan?
  - a. How do these services help people?
- 2. As someone who uses drugs, what has your experience been with hospitals and doctor visits?
  - a. What challenges have you experienced, if any?
- 3. What challenges have you encountered when accessing treatment, if any?
  - a. Has anything helped you access treatment in the past? If so, what?
- 4. What do you think the treatment system does well?
- 5. What do you think the treatment system needs to improve?
- 6. If it were up to you, how would you design the treatment system to work?
  - a. Prompts: What would it include or not include? Where would it be located? Who would work there?
- 7. Based on your experience, what do you think is needed to adequately meet the needs of PWUD and prevent overdoses?
- 8. Is there anything else you would like to add about any of the topics we've discussed today?

# APPENDIX F. HOSPITAL OPIOID TREATMENT AND RESPONSE LEARNING COLLABORATIVE PURPOSE AND OBJECTIVES

The purpose of the HOTR-LC is to bring hospital teams together around caring for people with opioid use disorder and/or individuals at risk of an opioid overdose with the stated intention of supporting and facilitating conversation around:

- Best practices;
- Program implementation; and
- Quality improvement.

The objectives of the HOTR-LC have been to move participating hospitals toward:

- Initiation of medication for opioid use disorder (MOUD) within emergency room or inpatient settings;
- Initiation of warm handoffs upon discharge to ensure continuity of care; and
- Initiation of naloxone prescribing and/or distribution of take-home naloxone for patients at-risk of an opioid-related overdose.