"I Didn't Get Here by Myself":

An Exploration of Opioid Use Among Older People in the United Kingdom and the United States Using Visual Methods

by

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Abstract

Background: Older people are who use prescription opioids are living longer in the UK and the USA, and contribute to a steadily growing rate of illicit opioid and polysubstance misuse among people over 50. Anecdotal evidence suggests older people with problematic long-term opioid use issues face difficulties in accessing physical and mental health services, entering drug treatment services, maintaining safe housing, participating in employment and staying out of prison. Evidence also suggests that older people with opioid use problems remain uniquely at risk for multiple and complex health issues which combine problematic opioid use with issues of imprisonment, discrimination, housing instability, overdose, poverty, social exclusion, stigmatization and victimization.

Further, there is evidence of older people with problematic long-term opioid use issues related to decades-long methadone prescriptions as stand-alone opioid treatment strategies in the UK. Opioid dependent people in the USA who would benefit from Opioid Substitution Treatment remain largely unable to access methadone and buprenorphine as treatment strategies for a range of reasons. Additional evidence suggests older people with problematic long-term opioid use issues in the UK and USA are stigmatized and denied access to healthcare and drug treatment services. Currently there exists a lack of published research exploring older people's perspectives and experiences with problematic opioid use, obstacles to treatment and pathways to sobriety. Older long-term drug users remain an under-researched population in both the UK and USA.

Aim: To explore the perspectives and experiences of older people with long-term opioid use problems and to identify the social, cultural and environmental conditions that contribute to both use and sobriety in Liverpool, UK and New Haven, Connecticut USA using visual methods.

Design and Setting: A visual ethnographic study using participant-generated photography and photo-elicitation interviews among older people aged 50+,

with 10+ years of experience using opioids including heroin from Liverpool, UK and New Haven, Connecticut, USA.

Method: Participant-generated photo-elicitation and photo-documentation methods were used alongside participant-researcher interviews in the field over a five-week period. Participant-generated photographs and participant interviews were analyzed using a novel Modified Interpretive Engagement Framework to support both narrative and visual findings. Capitol Themes and Capitol Works, which constitute the narrative and visual findings, together articulate the similarities and differences between the two international communities.

Results: A total of twenty-six people were recruited. Participants offered perspectives based on their personal photographs and lived experiences. Twenty-five participants completed exit interviews and reported a wide range of conditions that contributed to the development of long-term problematic opioid use, relapse and recovery. Thematic analysis revealed four major themes of interest: 1) adverse childhood experiences and adult traumas, 2) cyclical arrest and imprisonment, 3) housing and homelessness and 4) broken kin relationships. Themes were found to be overlapping and enmeshed issues of physical and mental health, which complicates solutions for long-term problematic opioid use in both communities. Differences between health treatment pathways, accessibility to health care services and *right to health* issues in Liverpool and New Haven were identified and found to result from a complex mix of long-standing policies, historical political divisions and free-market vs universal-coverage healthcare systems.

Keywords: Connecticut, drug dependency, drug misuse, drug use, fentanyl, heroin, Interpretive Engagement Framework, Liverpool, Liverpool John Moores University, long-term opioid use, Merseyside, Modified Interpretive Engagement Framework, New Haven, older people who use drugs, opioid addiction, opioid dependency, opioid recovery, opioid research, OPWUD, photovoice, Photo Voice, prescription opioids, opiates, recovery, relapse,

Thematic Network Analysis, United Kingdom, visual methods, veteran drug use.

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List of Abbreviations

AA	Alcoholics Anonymous
ACA	Affordable Care Act
ACMD	Advisory Council on the Misuse of Drugs
AIDS	Acquired Immunodeficiency Syndrome
APA	American Psychiatric Association
BFI	Betty Ford Institute
BON	Bureau of Narcotics
BOP	Bureau of Prisons
BPS	British Psychological Society
CBHSQ	Center for Behavioral Health Statistics and Quality
CBPR	Community-Based Participatory Research
CHIP	Children's Health Insurance Program
CMS	Centers for Medicaid and Medicare Services
CT	Connecticut
DEA	Drug Enforcement Administration
DDU	Drug Dependency Unit
DOD	Department of Defense
DRG	Drug Reference Group
DRW	Drug Recovery Wing
DVA	Department of Veterans Affairs
EMCDDA	European Monitoring Centre for Drugs and Drug Abuse
GP	General Practitioner
HBV	Hepatitis B Virus
HCV	Hepatitis C Virus
HIV	Human Immunodeficiency Virus
HHS	Federal Department of Health and Human Services
IEF	Interpretive Engagement Framework
IRB	Internal Review Board
IV	Intravenous
LGBT	Lesbian Gay Bisexual Transgender
LJMU	Liverpool John Moores University
MEH	Multiple Exclusion Homelessness
MIEF	Modified Interpretive Engagement Framework
MIEP	Medicaid Inmate Exclusion Policy
MHS	Military Health Service
MMT	Methadone Maintenance Treatment
NA	Narcotics Anonymous
NFO	No Fixed Address
NICE	National Institute for Health and Care Excellence
NHSS	New Haven Syringe Service
NHCHMC	New Haven Community Healthcare Mobile Clinic
NP	Nurse Practitioner
NSP	Needle and Syringe Program
NY	New York
OAT	Opioid Agonist Treatment
OMT	Opioid Maintenance Treatment

OST	Opioid Substitution Treatment
OUD	Opioid Use Disorder
OPWPDU	Older People with Problematic Drug Use
PAR	Participatory Action Research
PDMP	Prescription Drug Monitoring Program
PEI	Photo-Elicitation Interview
PHE	Public Health England
PGIE	Participant Generated Image Elicitation
PWID	People Who Inject Drugs
PWUO	People Who Use Opioids
SAMHSA	Substance Abuse and Mental Health Services Administration
SEU	Social Exclusion Unit
SUD	Substance Use Disorders
UK	United Kingdom
US	United States
USA	United States of America
VA	Veterans Administration
VHA	Veterans Health Administration
WHVA	West Haven Veterans Administration

Chapter 1: Introduction

"Recognition of the political-economic forces that impose patterns of suffering is the foundation for an applied critique of policy and services that persecute oppositional, marginalized populations in the name of morality." - *Philipe Bourgois.*

1.1 Introduction

As the world population continues to age, evidence suggests a growing percentage of drug users are also aging, creating challenges for drug treatment services and increasing the burden of delivering wider health, support and care services to those in need (UNODC, 2018; WHO, 2019). By 2030, the population of adults over age 65 in the US is expected to increase from 40 million to 72 million (USCB, 2020) and in the England and Wales that number will rise from nearly 12 million to 14.5 million (ONS, 2019). Growth is also expected in the number of older people with drug use problems (Carew, 2018; Han, 2009; Moos, 1995). Within the next decade, a host of health challenges will follow older people who use drugs into their later years (Age UK, 2019; Tilly, 2017; Keurbis, 2014; Wu, 2010).

There is no standard definition of an older drug user. The definition used by the European Monitoring Centre for Drugs and Drug Addiction (EMCDDA) defines older drug users as those aged 40 or older whose recurrent drug use is causing actual harms (negative consequences) to the person (including dependence, but also other health, psychological or social problems), or is placing the person at a high risk of suffering such harms (EMCDDA, 2010). In the US, increases in the population of older people who use drugs are often associated with the baby boom generation, born 1946-1964, now aged 58-76, who are credited with normalizing drug use behaviors in the 1960s and experienced increased rates of drug use as teens and adults over previous generations (Wu and Blazer, 2011). While the age at which an individual is considered to be an older person who uses drugs varies, research in the US has focused myopically on the baby boom age group.

Not all substance use is harmful, nor problematic. Older people with problematic drug use are defined, for the purposes of this thesis, as those aged 50 or older whose recurrent drug use is causing them harm or placing them at increased risk for harm (EMCDDA, 2010). The diversity of older peoples' lived experiences regarding problematic opioid use illuminates the difficulty in designing health treatment programs to suit and assist this unique and growing population. Despite their diversity, many older people who use opioids find themselves sharing similarities in the circumstances which led to health problems and harms. This growing cohort is the basis for the investigation.

Opiates are drugs derived from opium, such as heroin, codeine and morphine. Opium is the milky latex fluid collected from the bulbs of unripened opium poppies (*Papaver somniferum*). Opium is harvested from the plant by lacerating the bulb of an opium poppy in the field and collecting the milky substance. The latex fluid is then dried and processed to make heroin and other synthetic opioids (Labanca, 2018).

The term *opioid* encompasses opiates and molecularly comparable synthetic or partially synthetic drugs that act in similar ways to opiates, such as methadone and oxycodone. Although opium has long been used as a therapeutic remedy, the use of standardized dosages began in the 1820s with the scientific advances of Thomas Morson of London and Heinrich E. Merck of Darmstadt, Germany (Berridge, 2015). Oral standardized dosing of morphine gained acceptance in the medical establishment after the pharmaceutical industry expanded distribution worldwide during the 1830s and 1840s (Booth, 1996; Hodgson, 2001).

The 1853 invention of the hypodermic needle brought significant improvement in the administration of opium derivatives directly into the bloodstream, allowing expanded medical use (Booth, 1996). The injectability of opium and its derivatives also increased potency per dose, a factor implicated in the development of opiate dependence in later years (Macht, 1916; Hodgson, 2001).

1.2 Rationale for Study

The rationale for this study was to compare the lived experiences of participants in Liverpool and New Haven through photographs and interviews to understand the differences in social and structural environments, cultural conditions and legal policies that affect opioid use. Further, with a keen focus on health, the study prioritized an evaluation of living conditions, community health and issues of access to health care services as problematic opioid use affects individuals and the communities in which they live. The study also focused on how individuals live within social networks, deal with issues of discrimination, racial bias, marginalization and support systems.

This study used qualitative research methods to uncover the personal, biological, psychological and socio-cultural factors that contributed to and informed chronic opioid use among the participants. With a focus on the health of older people who used opioids, this study searched for answers to why people use opioids for extended periods of time, identified obstacles to opioid independence and which treatment strategies best facilitated long-term benefits to problematic opioid use.

This study cannot provide all the answers. A single American researcher cannot uncover every aspect of long-term opioid use, especially throughout the UK, which the researcher has never experienced. This study was also not intended to provide an overly detailed explanation of the UK and the US governmental policies toward opioid use and opioid dependence, as each country is in a constant state of active political change while the science surrounding opioid use continues to intersect with political and sociocultural obstacles. Predicting how governments may choose to understand and treat this public health issue in the future was not a goal of this study. However, some comparisons can be made using the experiences and perspectives of those willing to participate from Liverpool and New Haven. This qualitative study used participant-generated images and interview data from 25 participants from Liverpool and New Haven to guide the study and answer the research questions as they pertain to health and long-term opioid use.

1.3 Research Aim and Objectives

Research Aim

To explore the perspectives and experiences of older people with long-term opioid use problems and to identify the social, cultural and environmental conditions that contribute to sobriety, relapse and recovery in Liverpool and New Haven.

Research Objectives

To use participant-generated images production and photo documentation in collaboration with 25 people with long-term opioid use to discuss their personal experiences and help provide answers to four research questions. The answers to those research questions will be published and distributed to policymakers looking to improve the lives of older drug users.

1.4 Research Questions

1. What are the factors that contribute to long-term opioid use in Liverpool and New Haven and how do individuals experience these factors in their daily lives?

2. What services and treatments have been provided to people who use opioids in Liverpool and New Haven and what services and treatments do individuals want to participate in to improve health conditions and reduce opioid use?

3. What strategies for the reduction of opioid use among older people can be shared inter-culturally between Liverpool and New Haven to decrease rates of long-term opioid use?

4. What obstacles are implicated in fostering the continued rates of problematic opioid use in each location, and how do those structural factors differ between Liverpool and New Haven?

1.5 A Tale of Two Cities

Although opioid dependence and opioid-related mortality are widespread health problems in many parts of the world, this research focused on two particular communities with unique circumstances which contributed, in the past, to high rates of opioid use. Both Liverpool and New Haven have long histories of illicit drug use and the intravenous (IV) use of heroin. During the early days of the AIDS crisis, intravenous drug users occupied a unique position in the transmission chain of HIV, posing risks not only to other IV users, but also their sexual partners and offspring (Turner, 1989). The use of non-sterile injecting equipment was identified as a significant risk factor for HIV transmission as well as hepatitis and malaria (Des Jarlais, 1988).

HIV can spread from the infected to the uninfected through the sharing of blood-contaminated injection equipment (Ragonnet-Cronin, et al., 2018). IV drug users share injection equipment for a variety of reasons, primarily due to the lack of access to sterile injection equipment and the risk of criminal prosecution for possession of injection equipment (Moss, 1987). To combat the spread of HIV among the populations of IV heroin users, both communities instituted novel approaches that had been relatively untested; both cities began providing clean needles and syringes to IV drug users with the twin goals of decreasing bloodborne transmissions and educating IV drug users on the risks of HIV transmission through the sharing of non-sterile injecting equipment (Ashton and Seymour, 2010; Kaplan and Heimer, 1993; Kaplan and O'Keefe, 1993).

Liverpool was one of the first three UK cities to implement a needle exchange program for the IV-drug-using population (Stimson et al., 1988). The Maryland Street Needle Exchange in Liverpool began operations in October 1986 in a converted toilet within the Mersey Drug Training and Information Centre to combat the perceived threat of AIDS and HIV infection (Stimson et al., 1988).

At the same time, roughly 3000 miles west of Liverpool, New Haven, Connecticut was looking for solutions to combat their own heroin epidemic.

After three years of negotiations with the Connecticut state legislature, a bill was passed exempting the New Haven needle exchange program from laws that made IV needle possession a crime (Curtis, 2001). The USA's first legal needle exchange was opened in November 1990, operating from a single van delivering injecting equipment, condoms, bleach kits, and brochures with advice on preventing HIV infection throughout the city (Curtis, 2001; Kaplan and O'Keefe,1993).

Liverpool and many other communities throughout the UK continue to support the health of people who inject drugs (PWID) by maintaining needle and syringe programs (NSPs) in their respective communities.

Over the last 30 years, NSPs have expanded harm reduction and minimization policies, which focus on reducing all drug-related harms including the spread of HIV, HBV and HCV infections (Switzer, et al., 2015). Such policies also aim to minimize needle and syringe sharing and reuse, collect discarded needles and increase access to sterile paraphernalia (Torre, 2009). Most NSPs promote the use of condoms, provide relevant health information and assist with connections to health and drug treatment services.

New Haven also continues to support the health of PWID through the New Haven Syringe Service (NHSS), an offshoot of the New Haven Community Healthcare Mobile Clinic. The NHSS offers free sterile injecting equipment, collects used supplies and provides overdose prevention medications, health screenings and connections to services (Cheng, 2017). Needle exchange services are not widely available in Connecticut and are funded through federal, state and municipal grants (CTDPH, 2015). At the time of this submission, only 6 Connecticut cities—Hartford, Bridgeport, New Haven, Willimantic, Danbury and New London had needle exchange programs (NASEN.org, 2021).

Although rates of opioid misuse were significantly different between the two communities, both cities faced negative consequences associated with the use of illicit opioids and the impact problematic opioid use has had on the

social fabric of the communities (Rhodes, 2009). This study looked to the members of these communities to share their experiences, as well as to identify the barriers and benefits to opioid treatments and the conditions under which treatment programs operate effectively.

1.6 Background: The British System

The origins of today's drug policies in the UK are informed by many historical factors; the early importation of opium as an international commodity; wide commercial distribution of opium by wholesalers to shopkeepers, pharmacists, and grocers, more than a century of cultural acceptance of opium-based preparations within an unregulated market, and the power and political influence of medical doctors and pharmaceutical chemists in the late 19th and early 20th centuries (Lomax, 1973). Considerable economic wealth was built upon opium's broad medicinal qualities and wide social acceptance, which led to political alliances. Prior to the Rolleston Report of 1926, profiteers were largely able to circumnavigate attempts at controlling the distribution of opium-based products despite an increasing awareness of habitual drug use behaviors and overdoses arising from the unregulated recreational use of opium and its derivatives.

The British System is not a structure nor a formal set of policies, but a response to an opiate dependence problem that remained largely unchanged in size and scope until the 1960s. Unlike the expanding use of opium and cocaine in the United States at the time, evidence of significant increases in drug use in Britain, between 1900 and 1950 was not found.

The Rolleston Report of 1926 is widely acknowledged as a historical milestone in The British System of Drug Policy, an unofficial term now taken to mean, "a medically-based system of prescribing opiates to addicts, often on a long-term basis" (Berridge, 2005, p.7). Prior to the Rolleston Report, the British government made several attempts at curtailing the distribution of opium and its derivatives, morphine and heroin, through regulation and policy. The 1868 Pharmacy Act attempted to restrict the distribution of opium only to specialists,

but failed due to governmental exemptions to regulate companies that held patents on opium-based products (Berridge, 2005). Over 40 years later, the 1911 National Health Insurance Act also attempted to prevent widespread opium-based product sales through the use of a network model, supporting only National Health Insurance doctors, who could then prescribe opium for medically approved conditions as they deemed necessary (Gilbert, 1965). Both British Acts fell short of their intended effects, leaving the British government to deal with largely unregulated opiate consumption and the complex socio-cultural, economic and political climates of the early 20th century.

America was exerting political pressure on the UK during this period to influence the British System of Drug Policy and sway what came to be the long-standing decisions of the Rolleston Report. America, too, was interested in the control of dangerous drugs and sought to curtail the negative effects of habitual use at that time. Twelve years prior to the Rolleston Report, the Harrison Narcotics Tax Act (1914) was passed in the US, which established federal controls on the manufacture, distribution and sale of narcotic drugs, including opium and cocaine (63rd Congress of the USA, Dec. 1914). The Harrison Act indicted manufacturers, physicians, druggists, and habitual users for the nationwide conditions of habitual use at that time. However, some with political power were focused on the elimination of a secondary problem: an influx of immigrant workers from the east, particularly China, and the expanding and emerging African American workforce (Courtwright, 1992).

Propaganda from the period after 1911 identified the relationship between the passing of the Harrison Act and hostile political attacks on Chinese and African American cultures in the United States, both characterized by sensational false stories of heroin-and-cocaine-induced violent crimes against white Americans (Carstairs, 2000).

Evidence brought forward during the years prior to the Rolleston Report suggested that recreational use of opium and its derivatives was limited to medicinal product use, smoking among small socio-cultural clusters and the

rare, self-prescribing medical doctor and chemist who had become habitual users (South, 1998). The passing of the Dangerous Drugs Act in 1920 was an acknowledgement of the Home Office's responsibility to address drug dependence however, growing opposition to the use of police powers on the medical and pharmaceutical professions was met with considerable resistance.

By 1926, the Rolleston Committee had come to understand that the British System did not need to criminalize the behavior of these professions and instead needed the support and assistance of doctors and pharmacists in order to treat individuals with drug problems. The Rolleston Report concluded that doctors should maintain the right to prescribe maintenance doses for drug-using patients, recognizing both the low rates of habitual use of opium and cocaine in Britain as well as the considerable power and influence of the medical community, setting the stage for what is now described as the British System of Drug Policy.

1.6.1 The British System: Changes in the 1960s

Unlike the US, UK drug policies remained largely unchanged for the next 35 years after the Rolleston Report as evidence of increases in opium, heroin and cocaine were either not recognized or did not exist until the results of the second report of the Interdepartment Committee on Drug Addiction: The Brain Committee in 1965 (Bewley, 1968). The recommendations of the committee at that time were based on evidence that non-therapeutic heroin addiction was increasing and was a result of over-prescribing by doctors and the growing illicit market for heroin and other drugs.

The recommendations suggested the need for controls over the prescribing of opiates to habitual users, which lead to a new treatment model in the UK; specialty clinics were opened to treat those with drug dependence and general practitioners were denied the right to prescribe heroin and cocaine in an attempt to bring drug treatment practices under a more centralized infrastructure (Connell and Strang, 1994; Smart, 1984).

The proliferation of licit and illicit drug use continued during this time, and specialized treatment facilities expanded, both of which indicated the government's inability to curtail drug use. Legislative controls and the expansion of police powers to reduce drug use during this period were mostly ineffective at reducing overall rates, acknowledging the gap between the problems identified by the Committee on Drug Addiction and the solutions implemented to reduce habit-forming drug use (Berridge, 1998).

Governmental policy decisions regarding drug treatment strategies changed drastically in 1985 and 1986 when evidence of an association between intravenous drug use and HIV positive status was identified beginning in late 1985 (McCormick et al..1987). The Advisory Council on the Misuse of Drugs (ACMD), along with other institutions, began to suggest that the prevention of AIDS was more essential than preventing the injection of drugs. This established a fundamental change in drug policy, resulting in a return to the principles of the British System, and provided the opportunity for specialist drug services to offer needle exchange and education on safe needle practices while re-embracing the prescribing of substitute medications. This change directed help toward individuals at risk for the transmission of HIV (Robertson and Skidmore, 1989). This change in drug policy and the risks associated with HIV / AIDS together have been credited with ushering in harm reduction strategies within the UK and globally (Strang et al.,1997).

1.6.2 The Recovery Turn in the UK

Prior to the Labour party taking control of the UK government in May 1997, UK drug policy was primarily based on moving away from the harm reduction methods that characterized the HIV crisis and heroin epidemics of the 1980s and 1990s, toward the eradication of drug-related crimes which were thought to be stubbornly on the increase. (HM Government, 1995; UK Home Office, 2014, Research Report 79). While harm reduction strategies were effective at reducing heroin use and the transmission of HIV in many UK cities, of growing concern was drug-related crime and the need for increased community-safety

through tightening drug laws and increasing police enforcement. This change was reflected in new policies such as mandatory drug testing within the UK prison system and the continued expansion of third-sector Drug Reference Groups (DRGs) which combined drug treatment, social services and criminal justice agencies within a single institutional framework outside the longstanding NHS model (Duke, 2003).

In the UK, the concept of recovery from drug use was expanding in universal appeal at this time, although the Conservative, Labour and Liberal Democrat parties had their own agendas regarding spending priorities and political strategies. What remained evident during this time was the growing acceptance of wellness and quality-of-life measures in the overall assessment of physical and mental health outcomes. As those with chronic physical illnesses wanted social recognition for improved physical health, so too did those in recovery from drug dependence wish to be recognized as more than simply drug free or in diagnostic remission (White, 2009, Reeve, 2007). Those in recovery from drug use wished for a more definitive description of the positive changes that resulted from sobriety and reconnection to community.

A three-part consensus definition of *recovery* was developed at the Betty Ford Institute (BFI) in 2007, as a starting point for communication and understanding with and about the alcohol and drugs recovery community. The consensus definition was "*recovery from substance dependence is a voluntary maintained lifestyle characterized by sobriety, personal health and citizenship" (BFICP, 2007, p.223).*

In the fifteen years since the consensus definition of recovery was established at BFI, many new offshoots of addiction recovery have expanded beyond both professional addiction treatment and peer-led recovery organizations to a hybrid community of support specialists. These myriad specialists and their associations have come to offer new recovery community centers, recovery cafes, peer-assisted recovery homes, recovery-based social groups, as well as new-style collaborative partnerships with traditional drug service providers (White, 2008). While these recovery-based models have seen increased

acceptance throughout the UK and US, American drug treatment strategies have been slower to expand from more traditional, institutional fee-based systems to new hybrid recovery programs.

1.7 Background: The American System

The history of American Drug Policy starts in the 18th century with evidence of opium use by soldiers in both the Continental and British armies during the American Revolution (Quinones, 1975). The sale and distribution of opium-based products in the US to treat ailments such as diarrhea, cough, pain and insomnia were socially accepted as remedies through the 19th century (Boyd and MacLachlan, 1944). Patent-protected opium-based medicaments were marketed widely with some formulations marketed specifically to women and infants. Laudanum, an opium-based tincture developed in the 17th century by Thomas Sydenham of Britain, was imported and used to prepare surgical patients in North America (Dasgupta, 2019).

The American Civil War (1861-1865) brought about an increased acceptance of opium as an effective remedy for pain, as the Union Army issued nearly ten million opium pills to soldiers (Quinones, 1975). In addition to the wide distribution of opium pills, the development and use of the hypodermic needle solidified acceptance of opium and its derivatives to treat an expanding list of medical problems (Marks, 1929). By 1890, opiates were commonly sold in the unregulated marketplace, and habitual use in the US was widely recognized as contributing to the social problems of some large American cities (Musto, 1999).

Opium use was characterized in media and politics as an immoral vice, with criticism directed toward immigrants, particularly from China, who arrived in the western US to play a role in building the national railroad system and participate in California's gold rush period (Lyman, 2000). Rising sentiment against Chinese workers developed among American workers who competed for jobs and experienced decreases in salaries related to hiring Chinese labor as a low-cost alternative to American labor. The growing resentment and

hostility among the American working class toward immigrants led to political divisiveness, with anti-immigrant candidates winning favor in some parts of the country (White, 2002). Political propaganda around the turn of the 20th century blamed non-whites for white American problems. Propaganda against Chinese immigrants and people of color became increasingly commonplace, blaming both for the problems of society and characterizing each as drug abusers lacking in moral character (Lyman, 2000).

The origins of the moral argument in America regarding the use of opium can be found in the escalating divide between a nationalistic ideal of the white American and the unhealthy Chinese immigrant. A San Francisco law imposed by the Board of Health in 1878, targeted Chinese immigrants and banned the smoking of opium, thus moving its use into Chinatown's opium dens, which intensified the mysteries and gossip surrounding Chinese culture and led to the demonization of Chinatown as a haven for prostitution and illicit drug use (Trauner, 1978).

Over time, a portion of white American culture repeated the unsubstantiated accusations and laid blame on non-whites, particularly Chinese and African Americans, for the current social problems and the spread of opiate dependence (Lyman, 2000). By the 1890s, stories of "Yellow Peril" were published in print media, depicting white women at risk for rape and murder by deranged Chinese men who used opium (Tchen, 2010). Racial prejudice and its effects on American drug policy can be traced to anti-Chinese and anti-African American sentiment at that time, setting the stage for the passage of the Harrison Tax Act of 1914 (McCaffrey, 2019).

Prior to the Harrison Act, estimates of the number of opiate-dependent Americans in 1900 totaled 250,000 (Musto, 1999). Individuals with opiate-dependent health problems had limited access to remedies during the period, often limited to substituting one opiate for another stronger formulation. Established treatments at the time were based on voluntary and court-mandated institutional hospitalizations for withdrawal and detoxification. Hospitalizations lasted from days to years, requiring substantial fees for

treatments, while success rates varied drastically between drug treatment institutions (White, 1998).

Availability of services for opiate-related dependence left many lower-income and socially disadvantaged individuals with few options due to the financial cost of institutional health assistance. Doctors who treated patients during these years often prescribed stimulants, sedatives and other opiate formulations to combat relapse, fostering a cyclical process of dependence-detoxification-dependence and ensuring the likelihood of a patient's return to private, fee-based drug services repeatedly (White, 2009).

1.7.1 The Harrison Narcotics Tax Act

The Harrison Narcotics Tax Act was a federal policy written with considerable power and influence over states, which up until 1914, were largely responsible for individual drug policies and the enforcement of drug crimes in each state. The act placed all physicians and pharmacists in the US prescribing opium, opium derivatives and cocaine under the control of the Federal Treasury Department. While the act did not prohibit the prescription of these medications specifically, it did require that prescriptions be issued "in the course of professional practice only," acknowledging evidence of side-door retail sales, overprescribing and prescription selling (HNTA, 1914; Bertram et al., 1993).

The Bureau of Narcotics (BON) was created in 1915 within the Department of Treasury and began prosecuting doctors and pharmacists for violations and failures to report under the new provisions. Over the next years, political and social influence increased the strength and reach of the BON, blurring addiction maintenance, opium culture and anti-American immigrants with the United States' entry into WWI in 1917 as immoral threats to the national war effort (Musto, 1999). The results of these and other political decisions paved the way for the demonization of opium, heroin and cocaine, as well as the ratification of the 18th Amendment to the US Constitution, which prohibited the

consumption of intoxicating liquors in the United States for the next 13 years (Behr, 1996).

Although 1933 brought the 21st Amendment to the Constitution and an end to alcohol prohibition, the BON maintained tight controls on opiates and cocaine while continuing to prosecute trafficking and nonmedical prescription maintenance. The BON also continued to further isolate and stigmatize drug-dependent individuals through incarceration into the federal prison system (Courtwright, 2015). During this period, marijuana was federally listed as an illicit drug through the Marijuana Tax Act of 1937, and minimum mandatory prison sentences for federal drug crimes were imposed through the 1951 Boggs Act and the 1956 Narcotic Control Act. By the end of the 1950s, American Drug Policy had positioned itself into a double standard: one set of policies supported punitive mandatory sentences for opium, cocaine and marijuana while another supported the weak regulation of alcohol, tobacco and barbiturates, setting the stage for a widening political separation between liberal and conservative federal drug policies (Courtwright, 2015). In 1958, this political separation was clearly divided by reports submitted by the American Bar Association (ABA) and the American Medical Association (AMA), which questioned the use of police and penal system enforcement tactics over scientific, evidence-based medication maintenance trials, further separating liberal and conservative views as American society moved into the 1960s and entered the Vietnam War era (Musto, 1999; Courtwright, 2015).

1.7.2 The American System: Changes in the 1960s

The 1960s saw increasing social acceptance of the use of marijuana, opiates and other drugs during a period coinciding with the passing of Civil Rights laws in 1964 and 1968, which outlawed discrimination based on race, religion or nationality and ended long-standing housing discrimination policies (Musto, 1999; Johnson, 1998). By 1970, estimates of marijuana and heroin use among American GIs in Vietnam was 30-35 percent, but published articles from the period reported higher numbers, which contributed to the perception of a

growing American freedom to experiment with new drugs (Robins, 2010; Kuzmarov, 2006).

In 1971, due to evidence of heroin dependence among returning soldiers from Vietnam, detoxification programs were mandated for those individuals in need of drug treatment before returning home to the US (Stanton, 1976). An estimated 50 percent of returning soldiers who experienced heroin dependence in Vietnam used heroin on their return to the US and one in eight relapsed to heroin dependence after treatment (Robins, 2010).

The 1970s and 1980s brought additional laws which organized the regulation of opiates, stimulants, depressants, hallucinogens and cannabis, alongside the implementation of increased penalties for drug crimes. In 1988, the federal death penalty was reinstated for use in drug trafficking convictions and was expanded again in the Death Penalty Act of 1994, which extended capital punishment eligibility to 60 different crimes (Cunningham, 1998). The War on Drugs era, which began in the 1980s, represented a dramatic shift in the way law enforcement and the federal penal system handled drug use, possession, and sale. Mandatory minimum sentences and three-strikes-you're-out policies were enacted and enforced with increasing frequency. Between 1980 and 2003, the number of drug offenders in prison or jail increased by 1,100 percent from 41,100 in 1980 to 493,800 in 2003 (King, 2008). While strict federal laws regarding the sale, use and distribution of opiates, opioids and similar analogues remained in place, state laws overlapped medical prescription and distribution practices, complicating the unequal and imbalanced regulations between state and federal laws (Davis, 2019).

1.8 (Un)Diagnosis of Opioid Use in the UK and the US

The consistent use of heroin, opioid derivatives and other illicit drugs have been well documented in American and UK history for over 100 years (Musto, 1999; MacGregor, 1998; Hughes, 1972). The modern American opioid crisis, which continues to affect millions of users to this day, is associated with a nationwide change in pain management strategies brought about by the Joint

Commission on Accreditation of Healthcare Organizations (JCAHO) in 2000. At that time, healthcare organizations nationwide acknowledged the underassessment of patient pain and adopted new policies to treat and alleviate those subjective symptoms with effective prescription medications (Baker, 2017). The unintended consequences of this change, to include pain as “the fifth vital sign” brought increases in average opioid dosages, over-sedation of patients and overaggressive pain management to populations, resulting in escalating rates of fatal respiratory depression events throughout the US (Vila, 2005).

Since 2000, overdose deaths involving prescription and illicit opioids have nearly quadrupled, establishing parallels with the overall quantity of opioids prescribed by US doctors (Rudd et al., 2016). More than two million people in the US were dependent on prescription opioids, and more than 12 million people reported having misused opioids in 2015 (NSDUH, 2017).

The UK does not have an opioid crisis as does the US, but the UK does have an entrenched opioid problem, a slow and consistent increase in prevalence rates fueled largely by three factors. Those factors are: a rise in the use, duration and frequency of prescriptions written for opioids including fentanyl by GPs to treat acute and chronic pain since 2000; an increase in Opioid Substitution Treatment (OST) for problematic opioid use and opioid dependency including the use of prescription methadone by specialist drug services; and a growing and highly differentiated illicit drug market based in Liverpool and other UK cities (Robinson et al., 2019; Densley et al., 2018; EMCDDA, 2015). While these factors are widely implicated in the continued slow rise in opioid prevalence rates, the UK’s recent social acceptance of illicit opioid use can be traced, in part, back to the influx of imported heroin in the 1980s (Parker et al.,1988), an experience chronicled through first-hand accounts by the Liverpool participants over 50 years old, within this paper.

The differences in terms used to describe opioid use in the UK and the US requires a standard nomenclature. Since the nomenclature is not always consistent in international literature, the term *misuse* will stand as a general

term for problematic opioid use which occurs through the use of prescribed, family-acquired and/or illicit opioids.

While recognizing the importance of adopting person-centered language around the topic of opioids and the risk of using stigmatizing language in this thesis, the author recognizes significant variations and differences between the appropriateness of words used to describe conditions and diagnoses regarding drug use in the UK and the US. For the purposes of this study, the words *dependency* and *addiction* are interchangeable. While these words can be considered stigmatizing in the UK and the US, their use in the Diagnostic and Statistical Manual of Mental Health Disorders, Fifth Edition (DSM-V) and the International Classification of Diseases, Eleventh Revision (ICD-11), as well as in published peer-reviewed research, requires acceptance and tolerance for these and other possibly stigmatizing words.

The UK and the US have several distinct differences when looking at opioid use, mental health disorders and substance dependence. The DSM was developed by the American Psychiatric Association (APA) in 1952 to establish meaningful treatments and develop operationalized diagnostic criteria which encompass strategies for thinking about, studying, and providing care for patients with psychiatric illnesses (DSM, 2018; Suris, 2016). The DSM 5th edition was last updated in 2016 to aid, among others, mental health professionals throughout the world by developing a common language from which the diagnosing of individuals with mental disorders would be possible (Suris, Holliday and North 2016). The history of changes from the first DSM to today's DSM-V reflect advances in scientific understanding and the need to replace out-of-date diagnostic categories with new etiologically based definitions and to include scientific findings from psychological, psychiatric and neuroscience research (Regier, 2013).

The British Psychological Society (BPS), Public Health England (PHE), National Institute for Health and Care Excellence (NICE) and the NHS all recognize and utilize the DSM as well as the ICD.

There remains considerable disagreement on the US's over-emphasis on the use of diagnostic categories for patients and the US's reluctance to individualize treatment strategies (Allanson, et al., 2016). Acceptance of the DSM in the US is partially due to the US's global lead in neuropsychology research and in research publications, which often adhere to DSM constructs, resulting in widespread American professional familiarity with the DSM and ICD and thus, obligatory acceptance throughout the global community (Gornall, 2013).

In addressing the trends of increasing opioid use, the DSM-5 classification of Non-Medical Prescription Opioid Use Disorder (NMPOUD) was significantly altered from the previous DSM-4 classification to include most misuse and dependence criteria into a single new diagnostic category. Adverse health consequences for older people with NMPOUD include transitions to injection drugs and/or heroin use with related intravenous (IV) infections (hepatitis C, HIV), falls and fractures, cognitive impairments and drug interactions (Tulshi, 2016; Neale, 2016). Financial costs to society related to NMPOUD in the US are estimated at $72 billion annually (Hansen, 2011). The increasing use of illicit and prescription opioids in the US has caused state and federal institutions to seek ways of properly identifying the problem as well as addressing the responsibilities for care, treatment and service payments. The data illuminate a clear, problematic picture; without radical changes to decrease the number of Americans without health insurance, the rates of substance use disorders will continue to outpace available treatment services and consume state and federal health budgets (Compton and Baler, 2016; Abraham et al., 2017).

1.9 Differences in the Adoption of OST and Opioid-Related Services in the UK and the US

In the UK, local authority public health funding provides services for people seeking treatment for opioid use most commonly, through three different approaches: maintenance therapy, talk therapy and detoxification. As

indicated previously, these services are provided largely through specialized drug treatment services, known as Drug Dependency Units (DDU), which connect patients to clinicians for treatment and to help decide which methods of drug treatment are best for the individual. Support for opioid use treatments within the public health system can include maintenance therapy with an opioid substitute such as methadone or buprenorphine, inpatient or home detoxification with support, residential rehabilitation, talk therapy or support groups, all intended to be offered equitably and universally to registered NHS patients, based on geography, availability and resources. The NHS is challenged to provide drug treatment to those in need while keeping overall costs low and returning individuals to optimum attainable health in a timely manner. OST is widely accepted as an evidence-based, effective approach to problematic drug treatment which has essentially remained in place in the UK since before the Rolleston Report of 1926.

The American health care system does not provide wide opportunities to access government-funded drug treatment services for those with drug use problems. OST is not widely used, although the recent expansion of buprenorphine and suboxone distribution has seen small improvements in the availability of OST, particularly in politically motivated communities experiencing a rapid increase in opioid-related morbidity and mortality (Holly, et al., 2018).

To increase access to buprenorphine nationwide, the federal Drug Enforcement Administration (DEA) has expanded training opportunities to GPs and NPs with limited success in the expansion of services in some states (Azar, et al., 2020). Challenges continue to exist in buprenorphine access, especially among those aged 15-24, who saw significant declines in OST between 2010-2018 (Olfson, 2020). The majority of drug treatment programs in the US follow the same fee-for-services model as primary healthcare, making accessibility dependent on an individual’s ability to pay for services and leaving those without financial resources unable to access treatments.

1.10 Differences in Drug Treatment in the UK and US

Both the GP and third sector approaches to problematic opioid use are based on the recommendations of the World Health Organization (WHO) and the National Institute for Health and Care Excellence (NICE, 2020). Under optimum treatment conditions in the UK, care would follow the NICE Drug Misuse Management Plan, which combines recognition of opioid-related drug use with a four-point plan: opioid agonist medication (methadone, naltrexone and buprenorphine), psychological support services, family support services and contingency management after detoxification from opioids (NICE, 2020).

Alongside the NHS treatment model, are inpatient DDUs, mentioned earlier. Third sector drug treatment centers originated as a result of the second Brain Report in 1964 (Bewley, 1968: Kinsella, et al., 2009). Inpatient drug treatment programs and psychiatric units operate under the care of drug dependence specialists. UK third-sector care offer multiple models of drug treatment including 12-step, Minnesota, therapeutic communities, concept houses, religion-affiliated programs and others (Preston and Malinowski, 1993).

The NHS remains a publicly funded healthcare system delivering care to all citizens and legal visitors registered into a GP practice in the UK. Care at GP practices, hospitals and urgent care centers is usually free at point-of-service, covered by funding through general taxation and supplemented through National Insurance contributions. The NHS keeps health care costs low and equitable through a combination of bureaucratic decision making and rationing, making cost-effective decisions that affect NHS members universally. The NHS negotiates with pharmaceutical companies to deliver approved medications based on how well they work and the economic evidence of cost-effectiveness, including drugs for opioid substitution (Kotecha, 2019).

This process keeps tight control on medication distribution in the UK and reduces opportunities for opioid medications to be prescribed by doctors outside the patient-GP partnership. OST is largely supported and evaluated

through specialist clinics that operate in the *third-sector*, external to GP practices, which emphasizes a division between professions. The result is an attempt to prevent the overconsumption and misappropriation of opioid medications.

Unlike the UK, the American health care system is predicated on fee-based services through private insurance conglomerates that pool financial resources, utilize price reductions through volume, and offer a wide selection of in-network medical services. Insurers try to limit overall access to expensive treatments through tiered pricing of various insurance plans and coverage rates. Individuals who can afford more expensive treatments are encouraged to exercise their right to access them. This fractured design is based on market forces and highlights widespread inequality in US health care. The fee-based system provides wealthy patients the ability and right to pay for and seek advanced treatments and specialist services at additional personal cost, while excluding those without the financial resources to afford fee-based healthcare.

The American health care system encourages doctor shopping; if a patient is unhappy with a diagnosis received, the patient is encouraged to seek a second and third opinion, each for an additional fee. If a drug-seeking patient does not get a prescription for opioids on their first visit to a doctor, the patient is welcome to seek additional doctors until a suitable prescriber may be found. This stark difference between health care models highlights the paternalistic nature of the NHS model, which protects the UK citizenry from lax control of opioid medications and the risks of developing drug dependencies, which stands in opposition to the US *fee-for-services* model.

Since their inception, DDUs have evolved, expanded and adapted to changing market forces. Private drug treatment programs in the UK and US offer increased opportunities for residential detoxification and rehabilitation, decreased wait times for clinical appointments, increased privacy and opportunities for additional supportive and adjunctive therapies (Strang et al., 2005; Radley et al., 2017). Evidence suggests that multidisciplinary and coordinated care delivery models are an effective strategy on which to

implement opioid treatments and increase OST access. However, research directly proving the superiority of private drug treatment outcomes over public drug treatment outcomes is still uncertain (Lagisetty et al., 2017).

The US does not have a universal healthcare system like the UK and only recently enacted legislation mandating healthcare insurance coverage for nearly everyone, with exceptions (DPE, 2016). The US health care complex is a hybrid system where spending comes from a combination of federal, state and local departments, private insurance networks, businesses and stakeholders. Most US health care is delivered via the private sector, regardless of being publicly financed (DPE, 2016). Federal healthcare spending is distributed to states, mostly in block grants, providing flexibility in how states choose to spend federal funds. State and regional spending for healthcare is channeled through to privatized health care systems, public hospitals, GP practices, clinics and other local health institutions where patients access services.

Federal, state and regional policies shape the conditions under which US health care is mandated and provided at the individual level (Niloff, 2019). In 2017, 91.2 percent of people in the US had some form of health insurance coverage for all or part of the year, representing 294.6 million people (LiPuma and Robichaud, 2020; USCB, 2018). Currently, of those US citizens with health insurance, most are provided and paid through a shared commitment by employers and employees with the fees and contributions based on full-time status, job rank and years of dedicated service. For the last two decades, premiums have continued to increase substantially in cost, outpacing US inflation rates while health care quality has continued to decline overall (Niloff, 2019; DPE, 2016).

Those without health insurance coverage and those underinsured in the US have a profound impact on the US economy, representing a societal cost of nearly $250 billion per year (£188 billion) (Harbage and Furnace, 2009). As of 2016, 27.6 million nonelderly Americans have no insurance coverage (Foutz

et al., 2017). Those most at risk of being uninsured are low-income individuals, adults and people of color (Foutz et al., 2017; Glickman and Weiner, 2019).

The US health care complex has hundreds of healthcare delivery systems with the vast majority offering enrollment through an individual's employer. In 2016, there were 626 health systems operating in the US, incorporating 855,000 medical doctors and 2.7 million nurses (AHRQ, 2017; AHRQ 2016). The US does not have a universal social insurance program to ensure health services for the population as a whole. However, the government recognizes the health needs of certain populations based on income, disability, age and family circumstances. Federal assistance is distributed as Medicare, Medicaid and the Children's Health Insurance Program (CHIP) (Healthcare.gov, 2018; Heberlein, et al., 2013).

Medicaid is an assistance program for low-income patients' medical expenses, with considerable variability in eligibility requirements and exclusion criteria from state to state (Foutz, Artiga and Garfield, 2017; HHS, 2018). CHIP provides low-cost health coverage to children in families that earn too much money to qualify for Medicaid, recognizing the difficulty of health insurance affordability for impoverished families. Medicaid, depending on individual state policies, may extend coverage to pregnant women based on state coverage rules and state eligibility requirements (KFF, 2019). Each of the 50 US states oversee healthcare systems independently with significant federal regulatory oversight. Each state has differing criteria for eligibility, exclusion and access to treatment services primarily due to state political policies, population statistics and the strength of free-market forces (Navarro, 2019).

An example of the fractured nature of the US health care system are the 2,212,900 military and service personnel who currently serve on duty and the over 9,000,000 veterans who have previously served honorably in the US armed military services, which entitles them to federally funded health insurance through the Veterans Health Administration (VHA) (Dworsky et al., 2018). Veterans and service members under the VA delivery system are entitled to a wide range of services with negligible or zero out-of-pocket

expenses (Dworsky et al., 2018) The VA is widely recognized as providing above-average care compared to similar health care systems (O'Hanlon, 2017). The VA remains part of the Department of Veteran Affairs (DVA), situated within the framework of the Military Health System (MHS) and thus part of the Department of Defense (DOD), representing significant administrative redundancies that increase overall expenses (DVA, 2019; O'Hanlon et al., 2017). In some cases, VA services are unavailable to enrolled members, prompting VA outsourcing to private institutions for approved services.

Politics at the federal, state and local level of government play a significant role in drug treatment availability and accessibility through the allocation and discontinuation of funding resources. The Centers for Medicare and Medicaid Services (CMS) is the federal agency that administers Medicare and is a branch of the Federal Department of Health and Human Services (HHS), which monitors Medicaid programs offered by each state. In 2019, Medicare covered 60 million people with total expenditures of $630 billion (KFF, 2019; Cubankski et al., 2019). The funding comes from two Medicare Trust Funds: The Hospital Insurance Trust Fund, which collects money from payroll taxes paid by most American employees, employers, and people who are self-employed; and from the Supplementary Medical Insurance Trust Fund, which is funded through authorization by the US Congress (Hartman, Martin and Lassman, 2015).

The Medicare program is funded in part by Social Security and Medicare taxes paid on income, in part through premiums that people with Medicare pay and in part by the federal budget. There are limitations to continuous insurance coverage through Medicare which may restrict or limit access to health services and prescribed medications on a state-by-state basis.

Medicaid is prohibited by federal law from paying for care provided within US correctional facilities and it is the responsibility of each correctional facility to provide and pay for the care of individuals during periods of incarceration (SSA,1905(a)(A)). Thirty-three of the fifty states and the District of Columbia

(DC) have extended Medicare coverage in some form to incarcerated individuals, but this gap in health services continues to have negative health consequences for those incarcerated within the remaining seventeen states, including CT (Guyer, et al., 2019). Prison health services have been found to provide inadequate resources for appropriate testing, treatment and diagnosis of problematic drug use, substance dependency and mental health problems (MCHIPPAC, 2018; Gates, 2014; Rich, 2014).

1.11 The Current Opiate Problem

Opioids continue to carry a significant risk of abuse, misuse and death. Nearly half a million Americans died from drug overdoses from 2000 to 2014 (Rudd, 2016). In 2017, US opioid overdose deaths hit record levels, with a 9.6 percent increase from 2016 (19.8 per 100,000) to 2017 (21.7 per 100,000) (CDC, OOD, 2019; Huang, et al., 2018). In the England and Wales, combined data from the Office for National Statistics indicate that opioids remain the substance most commonly involved in drug poisoning deaths (56 percent) for 2017 and reveal a slight decrease from 2016 (3.6 per 100,000) to 2017 (3.5 per 100,000) (ONS, 2019). A comparison with the most recent data suggests the rate of fatal drug overdoses in Europe has increased slightly with over 80 percent of drug deaths involving opioids, although reports confirm these totals are missing unreported opioid overdoses (EMCDDA, 2019). Currently, the rate of death in the US is over six times larger than the rate of death related to opioid overdoses in the UK for reasons to be investigated in this study.

1.11.1 Liverpool

Opiate use in Merseyside, the metropolitan county which includes Liverpool, has increased steadily since 1980 when the UK Home Office recognized a total of only four residents who used opioids in Wirral, a large community that makes up the western portion of Merseyside. However, by 1985, the UK Home Office had revised its numbers to reflect a rapid rise to 1,800 people who used

opioids, with the possibility of the population being even larger (Parker, Newcombe and Bakx, 1988). Currently, the North West region of England, which includes all Merseyside, has the second-highest mortality rate for deaths related to drug misuse in England and Wales, followed by the North East region nearby (ONS, 2018; ONS, 2017).

Rates of drug misuse in the England and Wales were highest in three northern regions near Liverpool: The North East region had 8.3 deaths per 100,000 persons, the North West region had 6.5 deaths per 100,000 persons and Yorkshire and The Humber region had 5.5 deaths per 100,000 persons (ONS, 2018). In 2017, there were 1,164 deaths involving heroin and morphine in England and Wales, a decline of 4 percent and the first decline since 2012 (ONS, 2018). Despite deaths from most traditional opiates declining or remaining steady, a new synthetic opioid, fentanyl, is gaining wider distribution in the UK and the US. Fentanyl deaths in England and Wales have declined to 58 deaths in 2019 from a high of 75 deaths in 2017 (ONS, 2019; ONS, 2018).

1.11.2 New Haven

Located between the major port cities of New York and Boston, Connecticut's two major interstate highways have played an important role in the illicit distribution of drugs throughout the six New England states that make up the USA's northeastern corner. Heroin's historical availability in CT is strongly associated with the *New England Pipeline*, a notoriously popular interstate route from NYC to the Canadian border, which offers only two routes north and intersects in New Haven at the junction of highways I-95 and I-91 (USDJ, 2016). Highway I-95 provides distribution opportunities along the well-populated coastal communities throughout the states of CT, Rhode Island, Massachusetts, New Hampshire and Maine. Highway I-91 connects New Haven to the capital city of Hartford as well as to the states of Massachusetts and Vermont before arriving at the Canadian city of Montreal (USDJ, 2016).

In Connecticut, there were 955 overdose deaths in 2017, a rate of 27.7 deaths per 100,000 persons, nearly twice the US national rate of 14.6 deaths per 100,000 persons (NIH, 2019). The greatest increase in opioid deaths was from synthetic opioids, mostly fentanyl. Fentanyl overdose deaths increased in the USA from 79 in 2016 to 686 in 2017 (NIH, 2019). Deaths involving heroin increased from 98 deaths in 2012 to 450 deaths in 2016 but decreased slightly in 2017 to 425 deaths (NIH, 2019). CT deaths involving prescription opioids totaled 273 deaths in 2017, a more than four-fold increase from 60 in 2012 (NIH, 2019). Opioid-related deaths in CT are expected to continue to increase in the future (Kovner, 2019).

Opiate misuse has been well documented in medical, sociological and public health research for over 100 years, with the associated costs related to misuse and overdose in the US exceeding $1 trillion from 2001 to 2017. It is projected to cost an additional $500 billion by 2021 (Altarum, 2018). Opioid misuse has been implicated in various types of harm, including violence and murder, family deprivation, theft, and child abuse and neglect (Lund, 2016).

1.12 Context and Background

In order to access the differences between the participant experiences in Liverpool and New Haven, certain structural and institutional characteristics must be acknowledged. There exist certain distinctions between UK and US health delivery systems, as well as distinctions between US veteran healthcare and CT state healthcare systems, as well as additional disparities between the benefits available to those who qualify for Medicare and Medicaid, and those relegated to the US open-market's, fee-based healthcare.

1.12.1 NHS Access in the UK

While all citizens and registered visitors in the UK may receive healthcare services through the NHS, about 10 percent of citizens hold an additional private health insurance policy, often a corporate subscription through an

employer (Cylus et al., 2018). The NHS system has some similarities to Medicare in the US, although the NHS is a publicly administered system funded mainly through general taxation supplemented by National Insurance contributions (McKenna, 2018; Rahman, 2018). National Insurance, which became law in 1911, was Britain's first nationally organized health plan, originally providing working people access to GP and hospital care through joint contributions from employers, workers and the state (Thane, 2011). Over time, National Insurance expanded to provide pensions and unemployment insurance benefits to men and women, albeit with exclusions based on nationality, ushering in working-class protections to health and social services that continue to this day (Feldman, 1994). Currently, legal residents of the UK are entitled to health services regardless of nationality, payment of UK taxes, National Insurance contributions, registration with a GP or owning property in the UK (PHE, 2018). While the NHS largely deserves its reputation for being free at the point-of-use, contributions are required for some services, with exemptions for registered members under age 16, those over age 60 and others who qualify (HSCIC, 2016).

The NHS has limitations on specialist services, procedural hurdles to authorized treatments and substantial wait times for some routine services. Prescription medications, emergency visits, urgent care services, hospitalizations as well as dental and optical care are available through the NHS, although some services may have associated fees (NHS, 2018). The NHS is often both criticized and supported by the community which it serves, however, the vast majority of its recipients in the UK approve of the operation of the health care system as a whole and continue to recognize the benefits of the social healthcare model over other health care models such as those in the US (Robertson, 2017).

1.12.2 Health Delivery Systems in Liverpool and New Haven

When looking to compare individuals and families in the UK and the US with regard to combined homelessness and long-term opioid use, many variables

obscure a clear comparison. The differences between cultures and cultural norms, social policies, government-mandated protections and healthcare delivery systems hindered direct comparisons and associations. However, many of these differences are rooted in the healthcare delivery systems: The National Healthcare Service (NHS) and the USA's expanded system of privately and publicly funded healthcare. Ordinary residents of the UK are entitled to health treatment regardless of nationality, payment of UK taxes, National Insurance contributions or being registered with a General Practitioner (GP) in the UK (PHE, 2018). Participants from Liverpool had medical coverage, while participants from New Haven were not guaranteed the same benefits and protections.

The US on a national level, does recognize a need for universal health insurance for a portion of the population. To date, 38 states and DC have adopted Medicaid expansion to increase insurance benefits to a wider portion of residents, while 12 states have not adopted expansion and continue to restrict Medicaid expansion for various political reasons (KFF, 2021).

In contrast, the NHS is a single expansive health system. The Liverpool participants verbalized mixed feelings about the services they received and the nature and quality of substance treatment services, as well as the process of qualifying for substance dependence services. Many verbalized their experiences with UK substance treatment programs as difficult to qualify for, short in duration, disconnection between detoxification and rehabilitation and geographically inaccessible programs.

1.12.3 The Veterans Administration and Medicaid

The VA healthcare system is an example of the of a US health care system that provides comprehensive care to all members, while other US health care systems offer enrollees significantly less in comparison. Just over 2.2 million military and service personnel currently serve in the collective branches of the US military and over nine million retirees have served honorably in the US military services, which entitles both current and former service members to

federally funded health insurance (Blakeley, 2017, USDVA, 2018). Retired veterans and current service members under this healthcare delivery system are entitled to a wide range of services with minor out-of-pocket expenses. The health care systems for these individuals were widely recognized as providing above average care compared to similar, non-veteran health care systems. The Veterans Health Administration (VA) is part of the Department of Veteran Affairs and the Military Health System (MHS), which are controlled by the Department of Defense. There is evidence to suggest administrative redundancies in these institutions may increase overall health-related expenses, but remain widely popular to members of congress, often eluding reductions in financial support due to politics (O'Hanlon, Huang and Sloss, 2017).

Medicaid is administered by the Centers for Medicare and Medicaid Services (CMS) and is a branch of the Federal Department of Health and Human Services (HHS), which monitors Medicaid programs offered and run by each state. In 2019, Medicaid covered 64.7 million people with a total expenditure of $600 billion (Agarwal, et al., 2020). Federal funding comes from three sources: Disproportionate Share Hospital Payments, Federal Medical Assistance Percentages and Enhanced Federal Medical Assistance Percentages, each designed to decrease the financial burden of care for Medicaid recipients by states (Agarwal, et al., 2020). Medicaid services very widely from state to state according to the political willingness of state governments to provide benefits to those who qualify under federal guidelines.

Unlike the NHS, there are caveats to continuous insurance coverage by Medicaid which restricts access to some health services and prescribed medications. By law, periods of imprisonment in the US can result in ineligibility for Medicare and Medicaid Services, as federal and state prisons and local jails are mandated to pay healthcare costs during periods of confinement (MCPAC, 2018). An exception to this law exists for individuals needing inpatient healthcare lasting more than one day, a loophole some states were using and continue to use, to extend OST benefits to hospitalized,

justice-involved populations, which represents a rare victory for people in prison with drug use problems and prison healthcare systems (MCPAC, 2018).

Regarding drug treatment in the US, private healthcare insurance, VA insurance benefits and Medicaid all vary in eligibility, availability, medication accessibility and the duration of drug treatment services. Qualification for drug treatment services are not universal. Each state and health insurance system has differing policies for coverage and treatment options which are based on health insurance contributions and state law (Stoicea, Costa and Bergese, 2019).

Evidence suggests that the results of these policies are a fractured US health system with the participants' experiences reflecting less consistent healthcare and drug treatments and fewer opportunities for housing assistance, with some exceptions to those who have VA benefits. Liverpool participants verbalized little to no anxiety related to potentially losing health benefits, while New Haven participants often had stress and anxiety related to potential disqualification for drug use treatments, a consequence which directly contributes to cyclical, long-term opioid use.

1.13 Using Visual Methods to Investigate Older People Who Use Drugs

Previous research, particularly in the fields of sociology and anthropology, has established a number of emerging visual methods of data collection that support participant collaboration and the use of narrative explanations to describe, with deep meaning, the lived experiences of research participants (Harper, 2002). Additionally, photography and videography have been used for decades to elicit in-depth conversations and allow for a richer understanding and more detail about lived experiences than through person-to-person interviews (Schwartz, 1989).

Visual research methods change the traditional research dynamics of an open-ended interview by moving from an interviewer-interviewee relationship

to a three-dimensional, interviewer-interviewee-stimuli relationship, providing a second relevant communicative element that expands the conversation through new visual information while fostering a dialogue that traditional interview methods cannot deliver (Collier, 1957; Margolis and Pauwels, 2011).

This study incorporated a modified visual research method using participant-generated photo-elicitation and participant interviews regarding long-term opioid use to acquire specific knowledge from people who are local experts in drug use and understand how the communities in which they live are affected by opioids, crime, resources, laws and the larger drug economy.

Visual research methods have been described as *intrinsically collaborative*, fostering an opportunity for the researcher to explore the contents of a member-made photograph as well as providing the member photographer with an opportunity for self-exploration and critical dialogue with the researcher (Pink, 2006). This study was based on 25 individual, researcher-participant collaborations, each for a period of approximately five weeks; a period of time long enough to establish trust, encourage conversations about lived experiences with opioids and provide the participant photographers with enough time to capture images of the issues they consider worthy of inclusion and discussion within the project.

The methodology is rooted in the collaboration between researcher and participant to develop a team approach to understanding the issues facing older people who use opioids. In this study, as in *photovoice-type* research, documentary photography techniques were used to gain insight on issues related to the subjects through the perspective of the individuals' lived experiences. This intention, to capture the perspectives of the participants in photographs, sets this modified methodology apart from other types of photo-elicitation research by allowing the subjects the freedom to choose and include their personally made images rather than using other forms of visual representation which may not accurately identify the social, physical and environmental factors that contributed to their personal health status and life experiences.

1.14 Research Position and Assumptions

Based on the researcher's experience and background as a registered nurse in New Haven and community healthcare worker with experience in caring for homeless populations in New Haven, three primary assumptions were made regarding this study. The assumptions serve to identify a kind of framework that encapsulates both the positionality and perspective of the researcher and the reasoning behind the use of participatory visual research within an ethnographic investigation.

The first assumption is that opioid dependence is a chronic, debilitating disease of the brain and may require significant and repeated medical treatments by professionals. Opioid dependence may result from prolonged opioid use and may be characterized by periods of relapse and recovery before maintaining prolonged successful sobriety, if ever (Volkow et al., 2016; Gustin et al., 2015). This assumption is based on significant neurobiological evidence in published literature (Palmer, 2019; Mincin, 2018) and the assertion of individuals who live in New Haven and use or have used opioids regularly. The researcher's personal experiences with older people who use opioids suggest the transition from habitual illicit opioid use to practitioner prescribed methadone / buprenorphine is a major component of the most effective treatments strategies for opioid misuse and opioid use disorders (NHCHC, 2016; D'Onofrio et al., 2015). The researcher's experiences also recognize that many people have maintained successful long-term sobriety from prolonged opioid use without the need for detoxification and rehabilitation programs, nor the need for prescription medications to assist in maintaining sobriety.

The second research assumption is that stigma is an attribute, behavior or condition that is socially discrediting and is a major barrier which impedes individuals from seeking help with problematic opioid use (Mincin, 2018; Lloyd, 2013; Goffman, 1963). Experiences in New Haven by the researcher revealed that stigma was a consequence of (a) opioid dependency, (b) having been to prison and (c) rough sleeping. The sum of these consequences was found to

compound additional social problems, which then in turn, further exacerbate opioid and polydrug misuse (Terry, 2019; Minhee and Calandrillo, 2018). As identified through the researcher's New Haven community health nursing experiences, *stigma identity* was enacted and reinforced through everyday language, human interactions, institutional practices and local laws (Paquette et al., 2018).

Third, because opioid use is increasing in Connecticut and illicit opioid possession and use are crimes punishable by imprisonment, this study also assumes that Connecticut prisons are experiencing increases in the percentage individuals with opioid use problems (Bone, 2018). Anecdotal evidence supports the assumption that federal prisons and state prisons in the US further contribute to opioid-related stigma identity by supporting historic Victorian dogma; that problematic opioid and polydrug use is a moral failing. Participants who used illicit drugs for 10 years or more in New Haven and Liverpool faced issues of stigma and discrimination daily. Drug use stigma was compounded by experiences with imprisonment and homelessness.

Prisons in CT as well as the US hold a disproportionately large percentage of *men of color* for opioid-related crimes. This is in contradiction to conditions in the UK, where prison-deferred drug treatment programs are more commonly offered by the NHS and are conducted broadly within the UK prison system (Minhee, 2018; Marsden, 2017; Harding, 1986).

1.15 A Thesis Guide

This thesis was organized to present the research project in a traditional linear format, beginning with an introduction to the opioid problems in the UK and US, the health consequences which affect older people with long-term opioid dependence and the reasons behind the rising toll of opioid overdose deaths in both countries. Chapter one is an introduction to the subject of long-term opioid use and the history of opioid use in the UK and US. Chapter one includes a description of current opioid use statistics in Liverpool and New Haven, the differences in healthcare systems and how the use of visual

methods are an appropriate method for use in qualitative research investigations.

Chapter two is a literature review to present what was currently known about problematic opioid use among older long-term users, the ways problematic opioid use has been addressed or ignored in the UK and US, and how historical drug and alcohol treatment programs have evolved or been tailored to address the current needs of a rising population of opioid dependent older people. The literature review reveals the gaps which remain in the field of problematic opioid use among older people and provides a map to a potentially new understanding of the experiences of older people with long-term opioid dependence in Liverpool and New Haven.

Chapter three provides a historical background to visual research methods and informs the reader how those methods have informed past ethnographic investigations for the last century. Chapter three details the historical use of photography, motion pictures and video to bring context and deeper meaning to qualitative research. Chapter three describes how previous ethnographic research designs using visual methods informed the expansion and acceptance of various innovative research methodologies.

Chapter four is the methodology chapter which illustrates the step-by-step process followed by the researcher and participants throughout the qualitative research investigation. The methodology chapter describes the details, considerations, actions and ethical challenges that separated this innovative investigation from other visual research studies.

Chapter five presents the findings of the investigation as four *Capitol Themes*, and thirty-two *Capitol Works* which include accompanying descriptions and associated narratives to provide deep meaning. The thirty-two *Capitol Works* represent New Haven and Liverpool equally, as the most relevant sixteen images from each location were selected for inclusion using the Modified Interpretive Engagement Framework.

Chapter six presents further clarification of the interactions and conversations between the participants and the researcher, as well as revealing how the benefits of using participant-generated images for photo elicitation and photo documentation provided the researcher with critical insight and the authority to describe the experiences of the participants. Chapter six describes the most common subjects discussed in conversations, the visual content most commonly captured within the photographs and the subject matter the photographers intended to capture in photographs but were difficult or impossible to adequately translate from participant ideas to visual images. Chapter six illustrates how an innovative ethnographic methodology can produce a detailed understanding of people and their environments.

Chapter seven is a discussion about how and why rates of opioid use are disproportionate between Liverpool and New Haven, how the *right to health* is not guaranteed to American citizens as it is in the UK and answers to the research questions. Chapter Seven concludes with the ethical judgements and limitations of the visual research investigation and ideas about further research on the subject of long-term opioid use.

1.16 Presenting Findings

As indicated in section 1.15, the photographic and narrative findings are presented in Chapter 5 to introduce the reader to the findings of the modified IEF as *four Capitol Themes and thirty-two Capitol Works*.

These thematic and visual findings are presented separately, yet share a deep association between the participants photographs, experiences and intentions within the project. The collection of four *Capitol Themes* were the result of thematic analysis of the participant transcripts, narratives and field notes. The collection of thirty-two *Capitol Works*, sixteen from Liverpool and sixteen from New Haven were developed by partnering the participant quotes, often the photographer's own words, with the participant's experiences to deepen the meaning of the photographs from each research location and translate the

nuances, similarities and subtle differences between Liverpool and New Haven participant experiences.

1.17 Chapter Summary

In this chapter, the reader was introduced to the research aims and objectives and was provided with the four research questions which will guide the investigation. This chapter provided a brief history of opioids and the reasons why both Liverpool and New Haven are associated for the purposes of this study and why these cities require further investigation to compare the lived experiences of older people who use opioids.

In addition, this Chapter provided a brief summary of the current opioid problem in each region and best practices regarding general treatment plans for older people with long-term opioid use problems. Lastly, this chapter introduced the use of visual research methods and the reasons why visual research methods are appropriate for this investigation.

Chapter 2: Literature Review

"Furthermore, the study of the present surroundings is insufficient: the history of the people, the influence of the regions through which it has passed on its migrations and the people with whom it came into contact, must be considered." - Franz Boaz.

2.1 Introduction

Understanding the opioid use behaviors of people who use opioids (PWUO) and the influential factors associated with that use have long been of interest to clinicians and researchers in the field of drug treatment. Various theories, models and methods have been adopted to explain opioid use and the strategies implemented to improve the health of opioid-dependent individuals. These approaches to understanding drug use are not ubiquitous in the UK and the US, as socio-cultural, environmental and financial influences contribute to how each community identifies and prioritizes needs and provides assistance to their respective opioid-using populations.

Older people with long-term opioid dependency are under-represented in published literature and this review endeavors to understand why. This chapter looks to understand the opioid-using ecological environments of each community and the ecological environment's effect on individuals and their relationships. This study looks to understand, through previously published literature, the reasons why older people with long-term opioid use disorders experience problems with housing, relationships, jobs and prison. This chapter reviews the role and value of healthcare services for older people with opioid use problems, including within the prison health system. It is a goal of this study to uncover a direct relationship between opioid use, homelessness and prison so that the cycle may be broken and opioid related deaths may decrease in substantially.

This chapter will also explore published literature regarding the effects of opioid-related policies in the UK and US, and how laws may contribute to the personal experience of drug use stigma, discrimination and racism. This review also investigates the personal experiences of older opioid users on the

changing societal views of drug dependence and the complicated role of family, friends and connections in fostering improvements to personal health as they pertain to opioid misuse, relapse and recovery.

2.2 The Literature Review Process

This review aimed to examine existing evidence within the UK and American literature of the personal health experiences of older people with long-term opioid dependence and their personal health experiences with opioid recovery. Search terms were informed by the research questions introduced previously in Chapter One. Specifically, this review is interested in examining (a) the factors within each community that contribute to long-term opioid independence and recovery, (b) the drug services offered to / desired by older people with long-term opioid dependence in each community and (c) the factors that foster continued opioid dependence and negative health outcomes in each community.

Search terms were developed using four linked descriptive words as a phrase, characterizing the subjects under review. Each linked phrase included (1) a duration of drug use experience (long-term, 10 years, older), (2) a condition of drug use (addiction, dependence, illicit, problematic, recovery) and (3) a type of drug used (opioids, opiates, heroin). The phrases were searched between 25 January and 20 February 2017. The number of synonyms for each search phrase was deliberately limited in number to ensure that the author's assumptions on what should be included could be controlled while ensuring a comprehensive literature search and a realistically manageable collection of published research. Search phrases were entered into CINAHL, EBSCO/Medline, ProQuest, Science Direct and Web of Science. Inclusion criteria required published research to pertain to the personal experiences of opioid use, heroin use or long-term polydrug use in the UK or US. Drug use by people younger than 18, polydrug use without the use of any opioid and short-term use of any opioid were excluded from review.

The results of the literature search found 55 articles which met inclusion criteria and were used to frame what is currently understood about the experiences of older people with long-term problematic opioid use and how the experiences affect physical, mental, interpersonal, occupational, spiritual and emotional health.

2.3 Recovery Treatment and Services for Opioid Dependent Adults

An exploration into the health status of older people who use opioids requires acknowledgement of the subjective nature of *well-being* and *quality-of-life* appraisals. The use of any *well-being* or *quality-of-life* appraisal must come with consideration of the power dynamics inherent in appraisals and the weight of negative judgements in person-to-person and clinician-to-person interactions with stigmatized or at-risk individuals. Terms like opioid-related addiction, dependence, abuse and misuse suggest without merit, a departure from self-control, toward negative behaviors associated with opioid and polydrug misuse. Negative appraisals or assessments of a drug user's well-being or judgements about the motivations toward drug use behaviors are often a source of further stigmatization and emotional trauma that discourages some from seeking comprehensive medical treatment for drug problems (Zogmaister, 2013). In the past, the health status of drug users has been assessed at times on a linear scale, with the terms *relapse* and *recovery* serving to describe opposite sides in the assessment of drug use, rather than a more detailed assessment of an individual's physical, emotional and mental health.

Prior to the 2007 Betty Ford Institute Consensus Statement, recovery was defined as many things by substance treatment institutions. From the turn of the 20th century, institutional alcohol and drug recovery treatments were widely advertised and available in New York and London, as well as in other metropolitan cities. Lacking a cohesive basis in modern biological science, recovery at the time was broadly defined by *sobriety* or at minimum, the

diagnostic remission of symptoms (White, 2009; Musto,1999). This period was also characterized by newly developing laws that expanded the use of criminalization and incarceration to force drug users into mandated drug treatment and away from communities. The institutionalization of drug and alcohol dependent users was increasingly common and supported the entrenched cultural idea that excessive drug and alcohol consumption was a moral and personal failing. The Drug Asylum Period in the US, from 1920-1970 saw the progressive disbandment of large drug treatment hospitals, which had been created to hold drug users outside the community, toward a new recovery paradigm that recognized the benefits of culture, community and personal experiences in drug use treatments (White, 2009).

Over the coming several decades from,1970-1990, alcohol and drug recovery services became increasingly synonymous with 12-step programs and the mutual-aid movement which focused on the combination of specialist clinicians along with former drug users as peer-supporters and recovery guidance counselors. By the time the Minnesota Model was widely recognized as an effective modality for the treatment of diagnostic remission, the term *recovery* was being separately applied to the growing drug treatment industry which pushed social reforms from traditional institutionalization toward more open-minded treatment models which included new secular, religious and spiritual frameworks, some of which still exist with the field of drug and alcohol recovery.

By the end of the 20th century, the term r*ecovery* had come to encompass more meaning than a standard definition of sobriety or diagnostic remission. As stated in Chapter one, in recognition of this expanding sector of drug treatment services and the ever-evolving category of *recovery*, the 2007 Betty Ford Institute (BFI) Consensus Panel, worked to create a definition of r*ecovery* to improve communication and understanding between the international research community, health services institutions, substance users and the general public. That definition is,

"Recovery from substance dependence is *a voluntarily maintained lifestyle characterized by sobriety, personal health, and citizenship*." (BFICP, 2007, p. 223).

The 2007 BFI Consensus Statement goes on to define the words *sobriety,* "as abstinence from alcohol and all other nonprescribed drugs", *personal health,* "as improved quality of personal life measured by physical health, psychological health, independence, and spirituality", and *citizenship,* "as living with regard and respect for those around you socially and environmentally" (BFICP, 2007, p. 223).

William L. White, a member of the 2007 BFI Consensus Panel and considered a leader in the *recovery movement*, developed an expansive recovery paradigm which included issues of personal and cultural identity and the benefits of the process of transformational recovery, while stressing the importance of steady and incremental growth toward lasting community connections. This steady and incremental personal growth paradigm, in turn fosters self-confidence, self-reliance and re-integration into an individual's multiple, person-centered ecological environments (White, 2009). White's work in with the recovery community continues to influence current strategies for drug and alcohol treatment in may countries.

In the years that followed the beginning of the 21st century, significant changes in how recovery was framed in psychiatric practice, general medicine and third sector DRGs continued to expand the ideas emanating from recovery communities to include multiple recovery frameworks. Those frameworks included recovery maintenance programs, recovery initiation programs, secular recovery programs and religious recovery programs, each with a basis in helping an individual to assert themselves and mobilize inner strengths to change drug use behaviors and improve personal health.

Shortly after the Betty Ford definition, the UK Drug Policy Commission (UKDPC) expanded the range of routes to recovery to include *medically-maintained abstinence*, which further encouraged DRGs to enroll people who

used opioids in long-term substitution treatment, allowing for the appearance of overall reductions in the number of those with problem drug use and thus increased the statistical numbers of those who could be counted as adequately recovered from problematic opioid use (UKDPC Consensus Group, 2007, p.6) While evidence supports the use of OST for a successful *journey toward abstinence,* it remains counter-intuitive to suggest those using methadone or buprenorphine may be counted as recovered individuals from problematic opioid use in Liverpool.

The use of science-based recovery treatments and services for people who use opioids continued to grow as demand for drug dependence treatment options increased. While opportunities to participate in a variety of new methods of recovery increased, critics suggested that the commercialization and commodification of recovery had led more traditional recovery models away from personal and family healing, toward less expensive, single-modality, medication-assisted treatments. (White, 2012). Evidence suggests that participation in recovery programs for opioid dependency which used Opioid Substitution Treatments (OST) effectively, was associated with lower mortality rates, reduced overall opioid use, reduced risk of infections, reduced rates of incarceration and improved birth outcomes (Volkow, 2014). Further, published research findings show persistent use of buprenorphine treatment for 12 months or longer, decreased all-cause hospitalizations and decreased the risk of emergency room visits (Lo-Ciganic, 2015). The use of buprenorphine among criminal justice populations in controlled environments has also been studied and found to limit self-reported relapse to illicit opioid use, re-arrest and severity at the same rates as methadone, during incarceration (Magura, 2009).

While evidence suggests there is no “one-size-fits-all” solution to treating opioid dependency, there is sufficient evidence to assert that a combination of detoxification, medication-assisted treatment, therapeutic rehabilitation and outpatient counseling services, together may offer the greatest opportunity for a successful recovery (Parrino, 2015). Although this combination of treatments has proven to result in the highest rates of recovery from

problematic drug use, the course of opiate use treatment for individuals in the UK and the US often falls significantly short of these “best case” approaches to recovery (Miller, 2011).

Treatment strategies for opiate use problems are diverse and depend on several factors, including geographical environment, access to services, legislation and policies, economics, criminal behavior, and existing co-morbidities (Nosyk, 2015). A universal approach to opiate use treatments is currently unavailable and may highlight the stark differences in drug problems and policies between the UK and the US. There are significant differences between healthcare systems, drug policies, cultural norms, approved expenditures and government resources available in the UK and the US. Healthcare costs continue to escalate steadily in both countries, leaving local communities and regional governments to struggle amid the increasing need for services to combat and reduce problematic opioid use and opioid-related problems.

Rates of relapse to opioid use remain stubbornly high in the UK and the US, with estimates of relapse as high as 90 percent within one year, even after treatment (Nunes et al., 2018). Rates of relapse may indicate that poor follow-up care, limited access to services and proximity to opioid treatment services may not be sufficient to provide long-term opiate independence for individuals including those released from prison (Bailey, 2013). Rates of prisoner reuse of opioids on release from prison may also indicate a need for increased availability of counseling to support individual efficacy (UNODC, 2009). Although a tailored approach to opioid treatment services may offer the best opportunity for individual success, there remain limitations on the ability match universal services to individual needs, the cost of such services and the availability of resources, which may prevent the development of a universal treatment strategy (UNODC, 2009).

2.4 Literature on Older-Aged PWUO in the UK and US

In 2018, the population of adults age 50 or over in the US continued to increase, with an estimated 93 million people representing about 29 percent of the total population (KFF, 2018). In 2017, an estimated 14.5 million people in the US aged 26 or older needed substance use treatment in the past year however, data is limited on the specific number of adults over age 50 (McCance-Katz, 2019). In 2017, an estimated 2.1 million people in the US had an opioid use disorder, a calculation based on heroin use and illicit prescription opioid use under the definition of DSM-IV (NSDUH, 2017).

In 2018, the population of adults age 50 or over in England and Wales continued to increase with an estimated 24.81 million people representing about 37.3 percent of the total population (ONS, 2019). In mid-2019, an estimated 268,251 people in England were in contact with substance use and alcohol treatment that year however, data is limited on the specific number of adults over age 50 (PHE, 2019). In mid-2019 an estimated 164,208 adults in England were in contact with treatment for opioids or opioids and crack, representing 61.2 percent of those in contact with treatment for all substances (PHE, 2019).

It is estimated that between 26.4 million and 36 million people use opioids worldwide, with an estimated 2.1 million people in the US suffering from substance use disorders related to prescription opioid pain relievers and an estimated 467,000 with heroin use disorders (UNODC, 2012; SAMHSA, 2013; NSDUH, 2017). In both the UK and the US, the use of opioids is a difficult problem to address due in part to the illicit nature of the drug and the stigmatization of opioid use. Opioid use is hidden and often imperceptible as problematic use behaviors develop. People with OUDs face a multitude of negative health consequences that stem from issues of social isolation, social stigma and poverty, which further discourage the open discussion of heroin or the use of other opioids (Roe, 2010; Link, 2006).

Older people have been identified as a population at high risk for opioid-related problems in both the UK and the US for a variety of age-related reasons (Carter et al., 2019; Shaw and Smith, 2010). Increased rates of death related to opioid use among older people have been identified in small scale studies in the UK and findings support the utilization of NHS treatment strategies such as counseling in combination with Opioid Agonist Treatment (OAT) to reduce illicit opioid use and decrease associated harms among older users (Naeem et al., 2009; Skodbo, et al., 2007).

Evidence suggests many people over the age of 50 who use alcohol, prescription and non-prescription medications, and illicit drugs have aged along with their associated drug-using behaviors and have over time, developed long-standing alcohol and drug dependencies that are difficult to resolve (Roe, 2010; Beynon, 2009). Opioid dependence entails a progression in the frequency of use over time, from casual use to habitual use over an extended period and is informed by multiple causal pathways which include the interrelationship between social contexts, social influences and their effects on individual traits. Causal pathways are implicated and associated with individual opioid use behaviors through systematic evaluation using Ecological Systems Theory (Connell, et al., 2010).

While research on older people with alcohol dependence has been more widely studied, older people with long-term drug dependence is a relatively recent addition to scientific publications. Data on the growing population of older people with problematic opioid use is limited.

A recent qualitative study of IV heroin users in Scotland, which included participants up to age 57, found that 91% of participants had experienced homelessness, 75% had experienced one or more personal overdoses, 50% had attended a minimum five drug treatment programs, 90% suffered from depression, and over 50% experienced chronic pain (Matheson, et al., 2019). When discussing their physical and mental health status, a majority of respondents cited a need for mental health, physical health and housing services. Unlike the low rates of OST in the US, nearly 75% of respondents

reported currently receiving OST in Scotland. Health problems were frequent and secondary to the need for mental health services, with a majority of respondents having experienced gastrointestinal problems, respiratory compromise, arthritis and chronic pain (Matheson, 2019). These results show how the benefits of OST in Scotland, could be expanded in the US to benefit opioid users, where eighty percent of people dependent on heroin or prescription opioids do not receive any form of treatment (Stancliff, 2012)

Prior to the Scotland study, a qualitative investigation of the experiences of older drug users was conducted in Merseyside, among long-term poly-substance users aged 50 and older. The investigation sought to gain a clear contextual understanding of physical and mental health status and if changes in physical and mental health status were affected by the long-term use of drugs and alcohol (Roe, 2010).

Evidence of an association between ageing and social, psychological and physical health problems has led to an understanding that most health problems contribute to an increased risk for opioid use (Gossop, 2008). Evidence of an association between long-term opioid use among older people and poor health status appears to reflect that prolonged opioid use prematurely ages an individual in several ways. Studies indicate issues such as multiple physical and mental comorbidities, depression and social isolation contribute to long-term opioid use among older people (Beynon, 2009; Roe, 2010).

Ageing is not a simple, linear process, as chronological, biological, psychological and functional conditions affect human development (WHO, 2015). These conditions make the diagnosis of disease and illness increasingly difficult for healthcare practitioners as patients age into late adulthood. Problematic opioid use is often overlooked as a diagnosis when other comorbid factors are present (Palmer, 2018). Evidence suggests problematic opioid use has been, on occasion, misdiagnosed as depression, fatigue, insomnia or a mental health issue (Huhn, 2018).

As older people age, they are increasingly likely to use multiple medications for comorbidities that present in the later stages of life. This incremental increase in physical comorbidities over the life course and the medications prescribed to effectively treat those related symptoms, increase the risk of complex problems, especially an “iatrogenic triad” of polypharmacy, potentially inappropriate medication usage and drug-drug interactions (Novaes, 2017). The physiology of aging and progressive decreases in strength and independent mobility, make older adults particularly vulnerable to the effects of opioids, alcohol, and sedatives (Arndt, 2011; Le Roux, 2016). Additionally, ageing is associated with more degeneration-related physical pain and therefore provides more opportunities for exposure to opioid analgesics (Arndt, 2011; Le Roux, 2016).

The aging process of elderly people in both the UK and the US often complicates the diagnosis of drug dependence, which can be misdiagnosed in numerous ways including depression and dementia (Rollason, 2003; Huhn, 2018). Polypharmacy drug dependence among older people is also frequently misdiagnosed or unidentified, creating additional risks for drug dependence, overdose and the development of social isolation behaviors (Cornwell, 2009; Huhn, 2018). Social isolation among older people is a risk factor for morbidity and mortality, increasing significantly with age (Sorkin, Rock and Lu, 2002; Neale, 2008). Social isolation is often the result of losing social support networks and developing loneliness, a situation frequently identified in residential living facilities for older people (Grenade, 2008; Neale, 2016).

Among those who care for this older group of drug users are home caregivers, often adult-age children, who facilitate the doctor-patient visit. Frequently, adult children who provide home care to older substance users do not inform doctors of their elderly patient’s drug and alcohol use due to the stigma associated with substance misuse (Serre, et al., 2018; Green, 2014; Blow, 1998). In addition to missing this opportunity for disclosure to primary care physicians, poor screening by providers increases the chance of failing to identify older people with SUDs (Huhn et al., 2018; Joshi, 2019). Without a doctor-patient-caregiver collaboration, sufficient treatments for opioid

dependence among older people may never be recognized, and treatments never implemented, leaving comorbid factors to eventually manifest as health problems and negatively affect an individual's quality of life (Joshi, 2019).

SUDs in older adults are expected to increase dramatically in the coming years. Healthcare practitioners will need to consider new assessment strategies to screen for individuals with SUDs and physical and cognitive impairments (Lintzeris et al., 2016). The Substance Abuse and Mental Health Services Administration (SAMHSA), the agency within the US Department of Health and Human Services that leads public health efforts to advance the behavioral health of people in the US, released the Center for Behavioral Health Statistics and Quality (CBHSQ) Report in 2017 to present facts about substance use among adults aged 65 or older.

Among the most critical details of the report were, as previously noted, that estimates of older people with SUDs were expected to reach or exceed 5.7 million in 2020 (Han, et al., 2009); nearly 500,000 older people have used illicit drugs in the previous month; and that admissions to substance abuse treatment programs are increasing with greater rates of accepted drug use among this population (Mattson, et al., 2017). The CBHSQ report identified increases in emergency department visits by older people who use drugs. The increase in visits is primarily due to drug overdoses, comorbid health conditions exacerbated by drug poisonings and falls resulting in physical injuries from drug use and/or drug pharmacokinetics (Mattson, et al., 2017).

Older people who use drugs face a uniquely dangerous set of risk factors: an increase in health problems due to the aging process, poly-pharmacy interactions with prescription medications and illicit drugs, and the inability of medical practitioners to adequately treat mental health while simultaneously addressing physical pain issues and the risks of drug dependence (Rao and Crome, 2016).

Evidence suggests general practitioners and mental health professionals misdiagnose a percentage of older adults, especially those with dual

diagnoses (Lintzeris et al., 2015; Huhn et al., 2018). *Dual diagnosis* is a broad term used to describe the combination of both a substance use disorder and serious mental illness, a problem often associated with additional negative health conditions including physical ill-health, homelessness, unemployment and social exclusion (Webb, Wright and Galvani, 2018; Welch and Webb, 2018; Wilson, 2018; Crome et al., 2009; Neale, 2008; Gerada, 2007). Dual diagnoses negatively influence adherence to prescribed medications and are implicated in difficulties accessing proper services and treatments, poor quality engagement with services and worse prognoses than substance use and mental health conditions occurring independently (Crome, Sidhu and Crome 2009; Pycroft and Green, 2016; Chilton, Chrone and Tyson, 2018).

Studies indicate that current health services are ill-prepared to assess and care for dual diagnosis populations and such a diagnosis often discourages sufficient treatment in the prison environment (Crome, et al., 2009). UK research suggests drug workers may be reluctant to work with individuals with severe mental health needs and conversely, mental health workers may be reluctant to assist individuals with drug use problems (ODPM, 2004; SEU, 2002). The Bradley Report of 2009 suggested that dual diagnosis should be considered a normal condition and solutions should be found to improve both service provision and the coordination of care for this population (Bradley, 2009).

Correspondingly, UK specialist services for drug treatment are decreasing due to budget reductions and are being replaced by third sector (independent) treatment units which operate outside the margins of NHS care and may or may not be adequately staffed by specialists. Third sector specialist services may risk distancing older individuals with mental health needs and unintentionally facilitate declines in optimum treatment strategies (Roberts, 2020; Kalk, 2018). A solution put forward suggests that all new mental health research recognize the strong association between drug use, alcohol use and mental health needs as well as the complex strategies required to evaluate individual circumstances and treat multi-system problems (Roberts, 2020). This idea supports evidence of increasing problematic drug use among a

growing population of older people in the UK and the need for increased screening opportunities among older populations (Carew and Comiskey, 2018; Kalk, 2018; Moos, 1995).

An increased risk for morbidity and mortality has been identified among those diagnosed with both OUD and a serious mental health illness (Jones and McCance-Katz, 2019; Prince, 2019). OUD is defined as *"a chronic relapsing disorder that, whilst initially driven by activation of brain reward neurocircuits, increasingly engages anti-reward neurocircuits that drive adverse emotional states and relapse"* (Strang et al., 2020, p.1). Co-occurring problematic substance use and mental health disorders are increasingly common among older adults with OUD, which calls attention to the increasing need to adopt proper screening practices among the wide range of medical practitioners within separate health fields. This includes recognizing the need for drug and mental health screenings of older adults who identify as LGBT. Evidence suggests older adults who identify as LGBT suffer disproportionate risks for depression, anxiety, suicidal ideation, and posttraumatic stress disorder (Jessup and Dibble, 2012). Expansion of access to comprehensive medical services for individuals with suspected opioid use problems is urgently needed among all demographics but is critical for older populations (Jones and McCance-Katz, 2019).

In the UK and the US, studies have identified increasing numbers of older people with problematic substance use combined with physical and mental health comorbidities, engagement in risky health behaviors and increased social isolation (Beynon et al., 2009; Carew and Comiskey, 2018). The estimated growth of the older population with problematic drug use suggests a prolonged and increasing need for substance use treatment services, including treatments for multiple and complex diagnoses (Colliver, et al., 2006; Carew and Comiskey, 2018).

2.5 Literature Relating to the Health of PWUO and Homelessness

For the purposes of this thesis, the category of broad homelessness will include housing instability, houselessness, homelessness, rooflessness, couch-surfing, doubling-up and rough sleeping. A detailed assessment of an individual or family's particular conditions of homelessness will be based upon the ETHOS model from the European Federation of National Organizations working with the Homeless (FEANTSA). The ETHOS model allows for both the identification and classification of housing conditions.

The ETHOS model is based around a conceptualization of *home* that incorporates physical, social and legal domains of adequate, safe and secure housing. Homelessness and housing exclusion are conceptualized in terms of a deficiency within one or more of the following domains: *physical*: a lack of housing or adequate housing; *legal*: restricted rights or no rights to remain in accommodation; and *social*: accommodation or a living situation that impairs quality of life because it offers insufficient privacy, physical security or space for social relations within a household (Edgar, 2012).

There are four main living situations within the ETHOS typology: a) rooflessness, b) houselessness, c) living in insecure housing, and d) living in inadequate housing. Differences have been identified in published research in the UK and the US regarding homelessness terminology, governmental policies toward broad homelessness, recognition of individual and family housing needs and funding sources for shelter, short-term and long-term housing.

Individuals and families experiencing homelessness in the UK and US have been disproportionally affected by the opioid epidemic as many faced increased health risks resulting from long-term, problematic opioid use. Rough sleepers with problematic drug use were considered one of the most marginalized groups in society, often affected by complex physical and mental health needs and limited social support networks (Neale and Brown, 2015). Overdoses, primarily from opioids, have been identified as the leading cause

of death in this population (Baggett, Huang and O'Connell, 2013). Individuals with problematic opioid use are often unemployed or underemployed, which contributes to individual and family housing instability and compounds interferences with life responsibilities (Tolia, et al., 2015). Emotional trauma from adverse life events, lack of transportation, lack of continuity in health care services, lack of affordable and safe childcare, accidental ingestion of illicit drugs by children and institutionalized stigmatization by professionals contribute to poor health outcomes for families with problematic drug use, even as family unity is identified as a motivator for opioid treatment (Chatterjee, 2018; Tolia, 2015; Taplin, 2014).

Racism is the belief that certain groups are superior to other groups and that racial characteristics serve as fundamental determinants of human traits and capacities, while additionally, racism is a form of oppression based on a range of social characteristics which include gender (sexism), sexuality (heterosexism) physical and mental able-ness (ableism), age (ageism), class (classism), and nationality among others (Shopal, 2007; Paradies, 2006). There is significant published research which identifies how racial differences in wealth, education, employment and community quality limit access to healthcare services for people of color (Hardeman, 2018; Link, 2016; Feagin and Bennefield, 2013). When combined, racism and the *stigma of addiction* can have a serious negative impact on issues of housing and homelessness, rough sleeping, drug overdose, polysubstance use, unemployment, access to healthcare and imprisonment (Bennett, 2019; Hardeman, 2018; Link, 2016; Feagin and Bennefield, 2013).

Institutional racism, also known as systemic racism or structural racism for the purposes of this paper, involves interconnected institutions whose linkages are historically rooted and culturally reinforced to favor certain groups and oppress other groups. Institutional racism refers to the totality of ways in which societies foster racial discrimination through the reinforcement of inequitable systems (housing, employment, education, financial credit, media, health care and criminal justice among others), that in turn reinforce discriminatory beliefs,

values and distribution of resources, which collectively affect the risks associated with adverse outcomes (Bailey, 2017). Systemic Racism Theory in the US is characterized by five major issues: (1) the existence of a dominant racial hierarchy, (2) comprehensive white racial framing, (3) the existence of both individual and collective racial discrimination, (4) social reproduction of tangible and material racial inequalities, and (5) the existence of racist institutions integral to white domination of Americans of color (Feagin, 2010; Bennet, 2019). Evidence of direct or indirect structural racism in the US can be found in most institutions including the health system, the prison-industrial complex, employment, financial credit, as well as within additional institutional systems (Balko, 2020; Bennet, 2019; Bailey, 2017; Feagin, 2010)

With rising rates of combined problematic drug use and broad homelessness, including among older people, studies have looked to identify the structural and discriminatory barriers to drug treatment and the methods to lasting recovery for people with associated structural problems. A qualitative study in 2001 investigated the relationship between housing circumstances and drug overdose behaviors in Scotland (Neale, 2001). Among the findings from 200 PWUD were an association between overdose experience, polysubstance use and injecting drugs, which was identified in more than seventy-five percent of respondents. A majority of respondents reported periods of sleeping rough, living in emergency accommodation, staying in the care of others in the past. Additionally, more than one third reported adverse childhood experiences, including physical and sexual abuse, alcoholism and imprisonment. The reasons reported for being homeless included drug-using behaviors, broken relationships, eviction and difficulty in accessing drug treatment services. Lastly, ninety-four percent of roofless respondents reported previously being in prison, and eighty-nine percent reported using heroin (Neale, 2001).

A study investigated friendships and connections to emotional support for thirty PWUD, particularly opioids in England, to identify how and why respondents engaged in social contacts and communication with those outside their short-term hostels and substance-using worlds (Neale and

Brown, 2016). Respondents reported their friendships and social networks as important factors in preventing the establishment of loneliness, isolation and social exclusion. A third of the interviewees reported having no friends, a factor related to poor social, physical and cultural capital (Cloud, 2008). However, a majority of homeless drug and alcohol users in the study reported a desire for friendships, especially friendships with family-like friends. The findings stressed the importance maintaining family connections, developing and maintaining trusting and honest connections with others which may sustain and create new non-judgmental support networks. Interviewees identified the importance of using cell phones as a method of communication and connection to these friendships. Respondents also described the self-perception of being socially isolated and the negative health conditions that result from social exclusion when lines of communication are cut (Neale, 2015; Grenade, 2008; Gordon, 2000).

2.6 Literature Relating to the Health of PWUO and Prison Experiences

Over the last fifty years, the US has continued to acknowledge the need for drug treatment services to benefit of people in prison, beginning with the creation of the Treatment Accountability for Safer Communities in the mid-1970s which provided a bridge between the Criminal Justice System and the Drug and Alcohol treatment community (Taxman, Perdoni and Harrison, 2007). With the proliferation of the opioid epidemic in the US, the number of people in prison who use opioids regularly or have a SUD is disproportionately represented among those imprisoned in the US (Malta, 2019). The relationship between long-term opioid dependent people and recidivism is well-established in the literature (Malta, 2019; EMCDDA, 2012; UNODC, 2009; Taxman, Perdoni and Harrison, 2007). This literature review found no US data specific to total opioid use among incarcerated people, but it is estimated that approximately two-thirds of people in US correctional facilities have an OUD, yet only 4.6 percent receive OST, an indicator of how poorly the US correctional complex compares against prison healthcare in the UK (Malta,

2019; Krawczyk et al., 2017; Morgan et al., 2013; NCASACU, 2010; Mumola and Karberg, 2004).

Rates of OST in US correctional facilities remain stubbornly low and are a result of a failure to acknowledge the effectiveness of buprenorphine, methadone and other drugs for SUDs and the slow implementation of changes to deeply rooted, *abstinence-only* treatment strategies. Evidence suggests participants treated at correctional facilities with methadone maintenance treatment (MMT) or OST had lower rates of illicit opioid use, had higher adherence to OUD treatment, were less likely to be re-incarcerated, and were more likely to be working at 12 months post-incarceration (Malta, 2019).

In contrast to the 5% of people in prison with a SUD receiving OST treatment, all of England's 39 prisons offer individuals registered with the NHS access to OST and psychosocial treatment for OUD (Marsden, 2017). In the UK, illicit heroin is the most common drug used by individuals with OUD and treatment with OST along with adjunctive psychosocial interventions, has recently become the standard treatment available in all prison treatment systems, albeit with some limitations (Marsden, 2017).

Over six million Americans are now currently incarcerated, and over seventeen million felons or ex-felons make up the prison release population in the US (Massoglia, 2015). Imprisonment of people who use drugs is a major determinant in health inequality for individuals, families and communities, affecting family functioning, entrance to labor markets and poverty (Wildeman and Muller, 2012). Prison-released individuals without health insurance coverage often return to their local communities where persistent poverty, lack of adequate employment and affordable housing make finding a permanent home difficult (Wildeman and Wang, 2017). Many individuals imprisoned for drug use and drug-related crimes are identified as having comorbidities that were not adequately addressed while in the US prison system (Weinstein and Perlin, 2018).

Prison health in the US often lacks screening for undiagnosed conditions and often fails to acknowledge new health concerns, which leads to poor health outcomes and increased risks to physical health at the time of release (Baillargeon, et al., 2010). Studies have identified that in the UK and the US, populations of imprisoned individuals age fifty and older are the largest growing segments of the prison population and bring with them a growing need for health treatments (Bedard, Metzger and Williams 2016).

The consequences of inadequate healthcare services within the US correctional system place significant hardship on individuals after their release from prison. Previously incarcerated individuals are more likely to have experienced profound stress and trauma over their lifetime, to have a history of SUDs, experience homelessness, and have limited access to quality healthcare and education (NAO, 2017; Wildeman and Muller, 2012). In estimating the potential magnitude of the aging problem in US correctional facilities, it has been predicted that by 2030, incarcerated individuals aged 55 years or older will constitute more than one-third of the entire US prison population (USDJ, 2015). Without identifying and addressing the complex medical, social and environmental factors that contribute to the imprisonment of an increasingly aging cohort, this problem will continue to pose rising economic and social expenses on state and federal resources (Bavafa and Mukherjee, 2019; Porter, et al., 2016).

Research in the UK revealed that the overall prison population grew by fifty-one percent between 2000 and 2009; however, the population of individuals over the age of sixty grew by 216 percent, exceeding all other age groups (UN, 2009). In 2016-2017, 55,721 adults were in contact with drug and alcohol treatment services within the prison setting in the UK, with over fifty percent (29,626) presenting with problematic opioid use (PHE, 2018).

Upon reception into prison, individuals in the UK are assessed for drug treatment needs, with an average wait time of one day. Ninety-five percent of those individuals identified as having a drug dependency problem were provided with treatment interventions within three weeks of being assessed

for drug service needs (PHE, 2018). Sixty-five percent of opioid clients discharged from UK prisons were referred to treatment services upon release and twenty-seven percent were discharged having successfully completed treatment while in secure prison settings (PHE, 2018). Dropout rates for those in treatment in secure settings, across all substance groups, was less than five percent, highlighting the dramatic difference in opioid treatment opportunities between the UK and the low rates of OST and referral to drug treatment on discharge from US prisons (PHE, 2018).

Although the NHS strategy to maintain health is largely based on primary and secondary prevention strategies, incarcerated individuals are often limited in their ability to request health evaluations, especially evaluations by mental health professionals, leaving them vulnerable to depression, anxiety and a return to substance use (Tyler, et al., 2019). The impact of recent austerity measures on UK prison health has been implicated in diminished prisoner access to healthcare, the heightened rates of abuse of psychoactive substances and increases in participation in organized crime and violence (Ismail, 2020). New statistical evidence regarding substance misuse in prison showed small decreases in adults in contact with treatments services but increases in problematic crack use and new psychoactive substance use which should concern policy makers (PHE, 2018). Continuity of care for individuals leaving UK prisons is negatively affected by these new austerity measures. Continuity of care for individuals leaving UK prisons is considered as engaging with community treatment services within twenty-one days of release and has been identified recently by governmental evaluators as a poorly met need. While better than rates in the US, less than a third of those transferring to drug specialist drug services are currently meeting government-mandated scheduling goals (PHE, 2018).

A study assessing the mental health needs of people in prison in the UK identified a critical need for prison treatment services due in part to a severe increase in the prevalence of mental health morbidities in prison that has exceeded the general population outside prison (Bebbington, 2017).

Specifically, poor mental health services were identified; twelve percent of the interviewees met the criteria for psychosis; fifty-four percent met criteria for depressive disorders; twenty-seven percent met criteria for anxiety disorders, thirty-three percent met criteria for alcohol dependency and fifty-seven percent met criteria for illicit drug use (Bebbington et al., 2017). Additionally, sixty-nine percent of interviewees had two mental disorders or more. Moreover, in the year before imprisonment, only twenty-five percent of the incarcerated interviewees had used mental health services, acknowledging fundamental weaknesses in the NHS to provide adequate mental health care for all those in need (Bebbington et al., 2017).

A study published in 2017 investigated ten pilot Drug Recovery Wings (DRW) in UK prisons, which deliver abstinence-focused drug recovery services, each designed and based on local needs, target populations, size, therapeutic content and intensity of treatment (Lloyd, 2019). The authors of the study recognized there is no nationally representative, independent survey of self-reported substance use, which leaves investigators and policymakers to make estimations on overall rates of problematic drug use based on limited evidence.

What is clear from these investigations is that problematic substance users are greatly overrepresented among prison populations and that most dependent drug users, including those with problematic opioid use and OUD, reduce their illicit drug use during imprisonment due to reduced availability, cost and lack of cash. Inmates with opioid dependency issues are largely faced with forced detoxification or if available, participation in OST as illicit drug supplies are limited and of poor quality in prison (Lloyd, 2019; Malta, 2019; Fellner and Vinck, 2012). Prison-based OST health benefits are similar to those of community-based OST, which have been found to reduce overall heroin use, injecting and syringe sharing while in prison (Hedrich et al., 2012).

The impact of OST on post-release mortality rates, especially during the first month after discharge from prison, has been found to provide benefits to health. Investigations looking at rates of post-release mortality found that

fourteen percent of all deaths among those released from prison were associated with opioid use and opioid overdoses were reported as the leading cause of death for individuals in the first month of release from prison (Binswanger et al., 2013).

Buprenorphine and methadone-based medications are effective in treating people in prison with SUDs. Evidence suggests that OST for people in prison reduced drug-related mortality by seventy-five percent in the first four weeks after prison release (Degenhardt et al., 2014). Previously incarcerated individuals in the UK and the US are at significant risk of drug overdose at the time of release from prison. Studies have shown a high risk of drug-related death after release from prison with risk of overdose being greatest during the first four weeks after release (Binswanger et al., 2013; Binswanger, et al., 2007; Bird and Hutchinson, 2003). The leading causes of death among former inmates in the UK and the US are respectively, drug overdoses, cardiovascular diseases, homicides, and suicides (Binswanger et al., 2007; Binswanger et al., 2013).

Due in large part to the American *war-on drugs* and the relationship between draconian drug laws and strict sentencing policies, the US leads the world with the highest prisoner population overall and the highest rate of federal prisoners incarcerated for drug-related offenses (Mumola, et al., 2015). Of those people in prison convicted of drug-related crimes, less than 2% are provided the opportunity to receive OST for opioid dependence despite evidence that medications, specifically methadone, naltrexone and buprenorphine are among the most effective treatments for opioid use disorders (Bruce, et al., 2007). The societal costs of untreated opioid addiction among people in prison results in increased rates of opioid overdose, increased healthcare expenditures, lost productivity, increased community crime rates and additional expenses in drug enforcement (NIDA, 2012). While imprisonment presents a crucial opportunity for diagnosis, treatment and links to community-based recovery services prior to release, US correctional facilities are reluctant to expand drug treatment services beyond detoxification, which often results from mandated entry to prison and requires no specialization or additional

healthcare service employees. In the US, prisons serve as de facto, detoxification treatment facilities.

With approximately 1.3 million inmates housed in state prisons as of 2017 in the US and the landmark Supreme Court decision of Estelle v. Gamble in 1997, which guaranteed a constitutional standard of medical care for those in prison, there remain significant failures to court-mandated medical services (Mitnick, 2012; Sonntag, 2017). Currently, the state of CT does not guarantee the provision of dental care or mental health services beyond an initial mental health evaluation at the time of entry into a correctional facility. This obstacle to health services is sold to residents of CT as a cost-effective means for prioritizing basic health services to all inmates. Connecticut considers dental care and mental health as specialized medical services that would require off-site appointments and cause unnecessary disruptions in the day-to-day operations of any correctional facility, thus only available in extremely rare circumstances with authorization from officials (Sonntag, 2017).

Recidivism is often associated with substance use disorders and there is a well-established relationship between substance use and criminal justice involvement (Bennet, et al., 2008; Mumola & Karberg, 2006). There is also a well-established relationship between mental illness, substance use and criminal justice involvement, specifically post-jail homelessness (Henderson, 2014; Fries, 2014) There is a need for mental health services and substance treatment among those released from prison and at risk for homelessness (Henderson, 2014). It is this population that the researcher seems likely to encounter, due to the increased frequency this triple-stigmatizing experience among older people with long-term opioid dependence.

2.7 Intravenous Opioid Use

Injecting drug use is associated with an increased risk of morbidity through blood-borne infections, especially HCV and HIV, and through injecting-related injuries (Gilchrist, et al., 2017; Darke, Degenhardt and Mattick, 2007). Harm reduction strategies targeting the sharing of injection needles and equipment

were the primary focus of public health outreach programs in Merseyside, UK and New Haven, Connecticut US in the late 1980s (Stimson, et al.,1988; Curtis, 2001). Harm reduction strategies promoting education and awareness of the dangers and risks associated with illicit IV drug use were successful in decreasing overall rates of injection injuries through the 1990s (Wilson, Donald and Shattock, 2015).

In contrast, there are a total of six needle and syringe exchange programs in the state of Connecticut and one in the city of New Haven. As of 2021, according to the North American Syringe Exchange Network, 6 states—Alabama, Kansas, Mississippi, Nebraska, South Dakota, and Wyoming—do not currently allow needle exchange service for PWID (NASEN, 2021).

2.8 Chapter Summary

The literature establishes that older people who use opioids are under-represented in published research for many reasons, including the dated misperception that older drug users mature out of drug use as they age. The literature identifies that drug use continues for many people as they age and the reasons for persistent drug use are as diverse as the individuals themselves. Evidence suggests it may not be possible to decrease overall rates of OUD through legislation, prosecution and imprisonment, however, US federal drug policies have continued with a consistent, single-minded, abstinence-based approach to drug use since President Nixon declared a war on drugs in 1971, over 50 years ago.

Regardless of the development and expansion of increased penalties surrounding illicit drugs, the global marketplace for opioids and their associated economic forces have, over the last 150 years, provided consumers in the UK and the US with relatively consistent availability of opioids. The war on drugs has not succeeded in reducing rates of opioid use or opioid availability in the UK or US.

Historical governmental decisions in both the UK and the US

, introduced ideological differences and national policies that have shaped how and why each country has access to opioids. Cultural and sociological norms regarding the use of opioids have evolved over generations. Gradual cultural acceptance of drugs and drug use may suggest that increases in opioid use are little more than people making individual personal decisions about drug use, while ignoring the collective cost to communities. The unintended consequences of the over-prescription of opioids and the expanding distribution of illicit heroin and fentanyl are the results of free-market forces adapting to the changing economics of supply and demand in capitalistic societies. It is the intention of this study to investigate people with experience using opioids and to learn which factors may be changed to decrease overall opioid use in the UK and US.

Chapter 3: An Introduction to Visual Research Methods

"The best thing about a picture is that it never changes, even when the people in it do." - Andy Warhol.

3.1 Introduction

The use of visual research approaches has become more popular in the field of social science, in part for their ability to be inclusive of people considered vulnerable or marginalized and for those with disabilities. This research study sought to understand what it is like being an older person who uses opioids and how the experience differs between UK and US settings. This was done by using a qualitative approach, providing cameras to the participants and interviewing them about their self-made photographs and their personal experiences using opioids.

This chapter provides a brief history of visual research methods and how visual research frameworks have increased opportunities to expand social science research in new directions.

3.2 The Use of Photography in Qualitative Research

The use of photographic visual research methods has been found to provide opportunities for greater detail and deeper meaning about subjects of interest that may be overlooked in a more traditional (and one-dimensional), verbal-only interview processes (Rhodes, 2006).

The use of participant-made images as a visual research method was informed by the early work of pioneers like sociologist John Collier, anthropologists-turned-visual-anthropologists Margaret Mead and Gregory Bateson, and visual anthropologists Sol Worth and John Adair, all of whom established the use of visual methods to advance their knowledge about conducting cross-cultural research while morally and ethically relating to and

collaborating with the communities under investigation (Carvalho, 2011; Mead, 1975; Ruby, 1981).

Anthropology, which studies humans in societies under varying circumstances, searches for patterns and similarities between people, yet remains fundamentally critical of quick solutions and simple answers to complex questions (Eriksen, 2010). Ethnography, and by extension anthropology, require an emic and, at times, etic approach to research and support a sustained partnership between those conducting investigations and those being investigated. Ethnographic research requires the use of language and rationalization to develop an understanding of the social conditions being investigated. Photography, motion pictures and video have been widely and appropriately used in anthropological and ethnographic research (Rhodes, 2006, Harper, 2002; Schwartz, 1989; Collier, 1957). The use of photography and videography assist in the development of thick descriptions and deeper meanings which separate ethnographic research from other fields of social science that may depend more on objective forms of measurement to answer research questions.

3.3 A Brief History of Participatory Visual Research

Participatory approaches to social science investigations have proliferated widely over more than a century and early participants may not have been aware of their own participation in the development of definitive, historical works**.** Early innovative ethnographers Kurt Lewin and Alex Barvelas are credited with pioneering participatory social research through their work in the Harwood Manufacturing Plant in Virginia, USA. In 1939, Lewin and Barvelas made history by attempting to prove that democratizing a workplace could result in more profitability for a manufacturing business as a whole (Adelman, 1993). Lewin and Barvelas believed that the combination of social science and action-oriented research, when based on hypothetical “if so, then what” questions in partnership with community members, exemplified a new type of high-quality research based on democratic participation (Marrow, 1969).

Lewin and Barvelas rejected the positivist belief that researchers must study an objective world separate from the meanings understood by participants and instead favored observations of individuals participating within their social environments (Wallerstein and Duran, 2017). Lewin's extensive research studies combining psychology, human behavior and business practices are widely credited with the creation of contemporary *participatory action research methods* (Coghlan and Jacobs, 2005).

Many significant and varied participatory research projects followed the methodologies of early pioneers such as John Collier, John Elliot and the work of the Participatory Research Group by the International Council for Adult Education, each expanding participatory research throughout varied fields of science including ethnography, anthropology, education and public health. As research in the social sciences proliferated, participatory action research (PAR) frameworks were developed to complement social, cultural and ecological investigations. PAR frameworks have contributed to a multi-faceted understanding of the individuals under study, fostered health improvements and increased social protections through the development of multiple ethical and effective participatory research methodologies since their inception (Masters, 1995).

PAR has been described as a systematic inquiry that is collective, collaborative, self-reflective, critical and undertaken by participants within the inquiry (McCutcheon and Jung, 1990). PAR has been described as having four main themes: empowerment of the participants, collaboration through participation, acquisition of new knowledge and having the potential for positive social change (Masters, 1995).

Five decades after Lewin pioneered PAR, Wang and Burris developed what was originally termed as *Photo Novella,* a methodology designed to investigate the phenomenological experiences of marginalized individuals among a community using a novel form of participant action research, a practical and intentional approach to empowerment, feminism and documentary photography (Wang and Burris, 1994). Their early research

method entrusted cameras to marginalized women within their village communities to document their problematic lived experiences and provided a problem-posing education to identify shared needs and communicate those needs to policymakers (Wang and Burris, 1994). Wang and Burris evolved their research framework from the specific underpinnings of *Photo Novella* to *Photovoice*, as they prioritized research outcomes to identify community needs, accurately represent marginalized populations and promote positive policy changes (Wang and Burris, 1997). Photovoice maintains the flexibility to support many *community-based participatory research* (CBPR) designs that prioritize community consciousness, promote critical dialogue and inform policy development through stakeholder and policymaker collaborations (Wang and Burris, 1997). Photovoice strengthens the CBPR findings by allowing participants full autonomy to identify community needs, create and select participant-made images to inform policymakers and use both to inform local stakeholders and community members in order to foster positive changes within the community (Breny and McMorrow, 2021; Cheezum, et al., 2018; Plunkett, Leipert and Ray, 2012).

3.4 Photo-elicitation and Photo-documentation as Methods of Inquiry

Photo-documentation and photo-elicitation are two distinct methods of visual research; the former uses photographs to document and analyze a particular visual phenomenon and the latter uses photographs in interviews with the researcher to discuss items and issues of mutual concern (Rose, 2016).

Respondent-generated photo-elicitation, as a technique, uses photographs to generate discussions and create new knowledge based on the direct connection between the image and the image-maker. Different layers of meaning can be discovered when photo-elicitation is used as an investigative method, evoking deep emotions, memories, and ideas. *Photo-elicitation interviews* (PEIs) contribute trustworthiness to group research findings through triangulation, a process of confirming photographic meanings and

substantiating the lived experiences among other participants within the same research cohort (Boucher, 2017; Glaw et al., 2017).

The process of eliciting a verbal response from an interviewee is not limited to the use of photographs, as a growing variety of visual research studies have expanded to the use of video, film and sketched images while mobile phones and ever-improving global networks provide better sharing and communication opportunities (Pauwels, 2015). Historically, the term photo-elicitation was first documented in the 1950s by John Collier through his work with families and the investigation of suspected mental health issues, which successfully accomplished two related tasks: he used photos as a method of surveying people within their environments and as a method to expand the depth and meaning of issues discussed in narrative interviews (Collier, 1957).

Since Collier's early work, many social scientists have expanded the use of photo-elicitation methods to include the process of making images or image creation by collaborating with individuals to ascertain their particular understanding of their ecological environments (Harper, 2002). This opportunity for increased understanding through photographs was born from the process of *visual feedback,* a method that evolved from the use of personal pictures or family photo albums to gain an understanding of an individual's cultural setting and as a means to learn more about an individual's extended family as well as the social environment in which a family cohort is situated (Pauwels, 2013).

The combination of using photographic images in an interview to increase understanding of the experiences of the subjects and the use of partnerships in the research collaboration to develop those visual materials has been accomplished successfully throughout many fields of social science, particularly anthropology (Rhodes, 2006; Scherer, 1975). The use of visual research approaches strengthened their foundational roots in the early 1970s through the work of sociologists like Worth and Adair, who taught men from the Navajo Nation of Pine Springs, Arizona to use a 16mm film camera to document their personal experiences without the direct assistance of

researchers and was done outside the researcher's gaze. Their resulting study, *Through Navajo Eyes*, went on to solidify participant-generated photography as a trustworthy method for evaluating cultural phenomenology among isolated populations using only the participant-photographer to collect visual data about his/her personal lived experiences (Prosser and Schwartz, 1998).

3.5 Participant-Generated Image Production

Early adopters of participant-generated image production were interested in gaining access to cultural phenomena yet were also concerned about negatively affecting those populations and outcomes by intrusion and issues of problematic naturalistic inquiry (Prosser and Schwartz, 1998). Context-based methods developed by visual researchers offered effective community engagement strategies but required significant ethical modifications when working through stigmatized topics or among individuals with complex health care needs and disabilities. Given the potential for visual research methods to be used effectively among a variety of community engagement strategies, researchers must be acutely aware of the ever-changing and diverse needs of the population being studied, as well as the participants' risks for harm within any research investigation. The risks associated with the use of photographs cannot be underestimated when investigating issues such as victimization, stigmatization, marginalization and illegal activities, as the camera may exacerbate the oppressive conditions or simply create personally and/or structurally imbalanced power dynamics (Prinz, 2010). Photos often require anonymization to protect collaborative partners from being harmed through identification and stigmatization (Allen, 2015). Other concerns include the misinterpretation of the context in which images were produced, how they may be used, the longevity of images remaining in the public domain and their potential or lack of potential for future use (Prinz, 2010; Wiles, et al., 2012).

Over decades, the methods of participant-generated photography and photo-elicitation began to coalesce, and new qualitative social research designs

emerged. *Auto-driven photo-elicitation* became an increasingly popular method for investigating sociological and psychological phenomena, with photographs used as a reference point during interviews rather than as an objective representation of a reality that has meaning independent of the research discussion (Frith and Harcourt, 2007).

The vast field of qualitative social sciences has developed several variations and modifications of participant-generated photography methods, including some versions where social action and social awareness goals were prioritized above scientific knowledge goals, fostering issues of questionable priorities and research trustworthiness (Pauwels, 2015).

3.6 Using a Modified Interpretive Engagement Framework

The *Interpretive Engagement Framework* (IEF) is a rigorous visual research method for systematically analyzing participant-generated images through participant engagement. *Interpretive Engagement* is based on three stages of image analysis and five key elements of concern to support the development of substantive visual research findings. The five elements of concern are the researcher, the participant, the photograph, the context of image production and the audience who may encounter the image (Drew and Guillemin, 2014). These five elements may influence or be influenced by the other key elements and play an important part in contributing to the findings and overall analysis.

The three stages of the IEF follow a systematic method of image evaluation based on the image's influence on the five key elements listed previously. This visual research framework allows for the researcher's expertise to complement the analysis by contributing to what is known about the participants' intentions, experiences and ecological environment. Unlike other frameworks for evaluating participant-generated images, IEF appreciates the researcher's role in the investigation and affirms that the accumulation of new knowledge by the researcher comes through placing him/her in the best possible position for understanding how the member narratives and member images are relatable to the subject matter (Drew and Guillemin, 2014). IEF is

committed to understanding the deeper meaning of both the image and narrative through placing the researcher and participant photographer in equally important positions and allowing both to contribute to the accumulation of data for analysis through participant-led analysis in stage one and researcher-led analysis in stage two. IEF uses an audience-focused analysis in stage three as a final step before formalizing research results.

IEF has been successfully used in social science research and has been found to demonstrate rigorous and trustworthy analyses of participant-generated photographs (Laholt et al., 2017; Switzer, et al., 2015)

3.7 Chapter Summary

This chapter included a brief history of the use of photography in research, participatory action research, participant-generated photo-elicitation and interpretive engagement framework. This chapter explained the benefits of using visual research methods in qualitative studies to produce trustworthy results. Further, this chapter identified the benefits of using visual research methods over traditional interview-style research methods to provide deeper meaning while also acquiring new knowledge from individuals and researchers who understand and can interpret unique lived experiences.

Chapter 4: Methodology

"Neither the life of an individual nor the history of a society can be understood without understanding both." – C. Wright Mills.

4.1 Introduction

This chapter details the process used to collect data in this visual and narrative research study and details how the interactions between the researcher, gatekeepers and participants led to research findings about older people with long-term opioid use experience in Liverpool and New Haven. This chapter describes the steps used to start and maintain the researcher-participant collaborations, build trust between the researcher and the enrolled participants and the processes used to encourage the cohorts to take pictures of subjects and issues that they wished to introduce personally into the project. This chapter also describes the multi-stage process used to maintain the researcher-participant relationship through trust, cultural awareness and detailed planning. Many decisions were made during the data collection process, an inevitable fact of ethnographies and an expected obstacle that was managed through planning, flexibility and researcher reflexivity.

Lastly, this chapter describes the process of moving from participant-generated photographs and narrative interviews through the systematic process of categorizing and organizing data into themes that represented the participants' issues. This chapter precludes the dissemination of the findings which serve to bring the participants' personal issues to light and detail how the personal lived experiences of the individuals are central to understanding opioid use and how personal and interpersonal problems are subjective and dependent on the changing and dynamic characteristics of each person's ecological environment. A methods map is available in *Appendix 1*, which visualizes the systematic process used and serves as a secondary guide to ensure a clear understanding of the procedures and techniques applied to answer the research questions.

4.2 Role and Positionality of the Researcher

The researcher was interested in gaining new knowledge through both an emic and etic perspective of the participants' lived experiences with long-term opioid use and the consequences that prolonged opioid use had on individuals, interpersonal relationships and the activities of daily life. The researcher's role was central to this thesis and served to connect the communities of Liverpool and New Haven to the data in several ways. The researcher's role during data collection was to (a) choose gatekeepers and institutions for partnership; (b) protect the safety and anonymity of the individuals in the study; (c) personally interact with the participants from both communities without directing or leading members toward making particular photographs or giving specific answers; (d) remain compassionate, empathetic and trustworthy; (e) collect, protect and analyze the data for the development of research findings.

The role of the researcher in this study focused on engagement with participant collaborators using genuine interest and trust while promoting the collection of narrative data and discussion of the pictures. The researcher's role in this study posed significant ethical challenges, but also allowed for a deeper and more detailed understanding of the participants' lived experiences in both Liverpool and New Haven than may have been acknowledged through other methods of investigation. The MIEF research method was designed to intentionally place the researcher at the center of the research study with a universe-wide perspective of each participant's photographs, lived experiences and stories to explain how the answers to the research questions align with the research findings.

The researcher was a man, age 50, born in Los Angeles, California who began his nursing career in New York after attaining a BSN and RN licensure in 2005. For 7 years, prior to being a neurological and neurosurgical nurse in the largest New Haven hospital, the researcher was an Emergency Medical Technician (EMT) providing care in Los Angeles. The researcher was born and grew up in a lower socioeconomic and predominantly Hispanic and Asian, ELA

neighborhood. The researcher was bullied for being neither fully Hispanic, nor fully Caucasian by school and neighborhood peers. The two nicknames most often used on the teen-aged researcher by acquaintances were *Half-breed* and *McSpick*, both derogatory terms meant to convey that the researcher would always be, no matter the race or ethnicity of a group, an outsider.

The researcher grew up with alcohol, heroin, cocaine and barbituate use in his extended family in Los Angeles for about a decade starting in childhood and experienced interactions between heroin, extended family and law enforcement. The researcher experienced family members' struggles with heroin dependency and cyclical imprisonment related to drug crimes. The researcher experienced some of the consequences caused by heroin dependency and the ways the pursuit of heroin led to petty crime, lying and broken family relationships. At age 10, the researcher's home was burglarized and most of the valuable items were stolen by a family member who used the items to buy heroin before returning to prison within weeks of release.

The researcher has felt a strong connection to underdogs, outsiders and those in need beginning in childhood and continuing through adulthood. After becoming a RN, the researcher began participating in emergency preparedness and disaster relief responses in the US with Hurricane Katrina in 2005 to many affected areas in the southern US. The researcher has participated in community-based nursing and homeless outreach programs in Guatemala City, Port au Prince, Los Angeles, New York, Hartford and New Haven. The researcher conducted and published an IRB approved, community-based participatory research project in post-earthquake Haiti, a collaboration with nursing students from FSIL to identify housing and health needs in Léogâne, the epicenter of the 2011 earthquake that killed over 100,000 Haitians and destroyed 90% of homes and businesses (McRiley, 2012).

The researcher's past experiences with CBPR, long-term heroin use and visual research methods brought many necessary foundational issues together in the development of this modified framework. The researcher's

experiences with the effective use of Photovoice methods and the success of implementing a qualitative research framework in a foreign language made the transition to this thesis possible. This thesis and the centrality of the researcher within the qualitative design is the result of life experiences, formal education and the need to design an ethical approach to learn from a group of experts in drug use, who have been stigmatized, marginalized and rendered powerless for reasons largely beyond their own control.

4.3 Ethical Protection: Redaction for Participant Safety

Maintaining confidentiality and anonymity while collecting participant-generated photographs, listening to detailed accounts of drug use experiences, learning about member's social networks and local drug economies presented many unique safety challenges to both the researcher and the study population. After carefully considering the risks associated with people identifying participants through the photographs and narratives, the process of collaboration and the money paid at the exit interviews, the informed consent process and forms were approved by the LJMU Internal Review Board (IRB) for this research.

In order to guarantee safety and adhere to ethical standards, all photographs used in the study were submitted by the participant photographers for use in this research after being informed about, and in support of, the study's goals. The participants agreed to participate and provided written consent to use their photos and interviews in this study.

All institutional names, individual names, street names, park names, businesses and most locations were changed to protect the anonymity of the participants. When necessary, participant-generated photographs were blurred and/or cropped to protect the identities of people within the photographs.

4.4 IRB Approval to Conduct Research

An application to conduct research was filed with the University Research Ethics Committee (UREC) in April 2016. The UREC considered the application and granted ethical approval on the understanding that; (a) any adverse reactions/events which take place during the course of the project are reported to the Committee immediately; and (b) any unforeseen ethical issues arising during the course of the project will be reported to the Committee immediately. No reportable, unforeseen ethical issues arose during the project. The IRB application was approved as: 16/CPH/004 - McRiley, Mark (PGR). *Addiction, Treatment and Recovery Among Older Opiate users: A PhotoVoice study in Merseyside, England and Connecticut, USA.*

4.5 Visual and Thematic Analysis Using Modified Interpretive Engagement Framework

Before a detailed description of the thematic and visual analyses are presented, figure 1 (below) provides a visual guide to aid the reader in understanding the processes undertaken to arrive at the research findings. The Methods Map follows two paths, visual data and narrative data to arrive at the final analysis, recontextualization and member-checking, which brings the visual and narrative data together to answer the research questions.

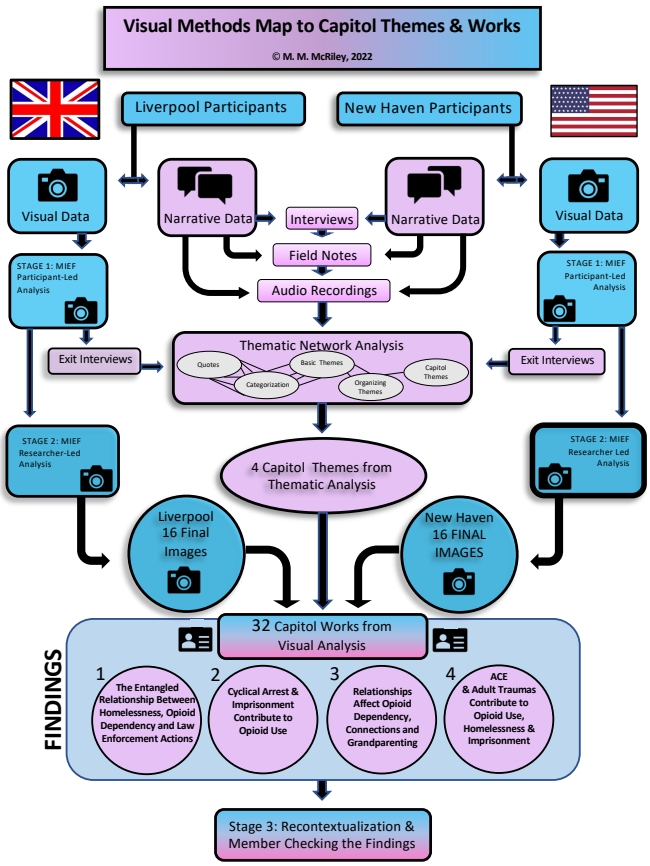


Figure 1. Methods Map

A modified version of Drew and Guillemin's Interpretive Engagement Framework was used for the three-stage process of data collection, data analysis and the confirmation of visual and narrative findings. As described previously, the visual analysis followed a systematic method of image evaluation based on the image's influence on 5 key elements. To aid in the understanding of this MIEF method, a process map has been included below to guide the reader through the framework (p.110).

The MIEF includes both a *thematic analysis* of the narratives, notes and transcripts and a *visual analysis* of the photographs and their deeper

meanings. The results of the overarching MIEF include both *Capitol Themes* and *Capitol Works*, which are the results those analyses. Together these analyses within the MIEF framework provide a much needed example of a trustworthy, reliable and objective visual design for application in future ethnographic research, CBPR and Photovoice-type projects to answer qualitative research questions.

4.6 Recruitment and Enrollment in New Haven

The process of data collection in New Haven was undertaken before beginning data collection in Liverpool as a way of beginning the process within a community the researcher better understood culturally, socially and geographically. As a street-level community health worker, public health professional and registered nurse at a New Haven hospital, the researcher had a unique position from which to evaluate the local community. Through experiences in the hospital and in the community, the researcher understood some of the issues surrounding opioid use, overdose, drug dealing and rough sleeping in parts of the New Haven community.

Participants were recruited in New Haven gradually over a seven-week period through the assistance of four gatekeepers with connections to three different drug services. The consenting gatekeepers from New Haven were drug counselors or social workers. These gatekeepers served a two-fold purpose to the participants and the researcher by connecting individuals they felt were safely able to participate in the study while maintaining a level of supervision and safety for the participants through the collaboration period.

Gatekeepers selected potential participants based on their professional opinion of their willingness to participate, ability to maintain consistency in semi-weekly or weekly meetings with the researcher, ability to remain safe with a digital camera and having had authentic life experiences that pertained to older people with long-term problematic opioid use.

Each potential participant was informed about the project in the company of the gatekeeper and was provided written documentation about the project, their role in the research and the risks and rewards of participation in the collaboration. Each participant and gatekeeper read and signed their informed consent documents together and each was given copies of the documents to take home as a record of the collaboration. Each enrolled participant was provided with a loaned digital camera for use in the project and was shown how to operate the digital camera and specifically, how to erase a photograph from the device. Demographic data on the participants from New Haven is included in *Appendix 5.*

Erasing photographs was an important first step to the photographic collaboration as the participants alone had the authority and ability to include or exclude photographs used in the study. This important first step was designed to foster research trust and benefit the relationship between the researcher and the participants. Learning how to erase pictures was a form of empowerment. Teaching participants how to erase pictures instilled trust in the researcher.

The participants left the first meeting with a functional digital camera to capture and communicate ideas and perceptions that could transcend traditional conversational boundaries. They had been entrusted with cameras and asked to express their ideas and expert opinions regarding drug use through picture taking; utilizing methods in visual research that will improve on more traditional, interview-style investigations.

4.7 Stage One: Participant-led Engagement in New Haven

Participants were encouraged to take photos of anything of interest: subjects they would like to discuss, family and friends, places they visited in their communities and events that happened in their environments. One week after enrollment, each participant's first meeting was scheduled to share photographs, ensure the proper functioning of the cameras, and evaluate each participant's willingness to continue in the project. These meetings were

typically scheduled to coincide with a regular, pre-scheduled appointment back at the institution or clinic where the gatekeepers worked. Using the clinics as a location for the second meeting ensured a level of safety and confidence in the collaboration and showed participants that the researcher was punctual, dependable and interested in their thoughts, opinions and photographs.

4.7.1 First Photo-sharing Meetings in New Haven

The second meetings were the first occasion to share photos, an important opportunity to begin building trust between researcher and participants. The second meetings were often described later by the participants as awkward because it was their first opportunity to discuss their personal histories as older people with long-term opioid use experience and their first opportunity to share personal photographs. The subjects and conversations surrounding the first photographs varied widely in content and topic as the researcher had no preconceived requirements, which let the participants lead the decisions about what to take photographs of and how subjects and issues within the photographs were described. Uncertainty by the participants and support and encouragement by the researcher, often characterized the discussions about life experiences and personal histories at the second meetings.

Nearly every second meeting had some similarities: participants were often uncertain of their photographic choices and hesitant to believe their photographs were suitable for inclusion in the research. The researcher was genuinely interested in all photographs and openly appreciative of each participant's commitment to the study. Each photograph submitted provided an opportunity to see issues from the participant's perspective. Regardless of quantity or quality, the researcher explained how the participant's photos were of good quality and how their photographs contributed to benefit the visual research project.

Often the sharing of first photos led to discussions about how to keep subjects in focus, how to turn the flash on and off, and how to frame a photograph in either landscape or portrait style. Only once in New Haven did a participant

have zero photographs to share at the first collaborative meeting. Ironically, his issue was that he was separated from his personal items against his will by law enforcement, a consequence of rough sleeping in a New Haven park. The participant collected the loaned camera from police before the second meeting to prove his commitment to the collaboration. This was an example of how the collaborative partnership was building trust in both directions, between researcher and photographer.

At each meeting, with the participant photographer's permission, the images were copied from the loaned digital cameras to the researcher's laptop for safe storage. The photographs on the digital cameras were not deleted until the participant completed the exit interview or left the study, to allow the participants the opportunity to see their own photographs as an accumulating body of work and reflect on their own collections.

Most frequently, the second meetings involved the participants telling their stories of how they began using drugs, and how their lives have been negatively affected by drug use over time. Each second meeting was done independently of other participants to ensure confidentiality and to further develop trust between the researcher and participant. It was common for the first photo-sharing meetings to include images for inclusion in the project and also images of things that participants simply took pictures of, outside of the project. Personal use of the digital cameras was encouraged by the researcher. This demonstrated that participants enjoyed taking photographs, suggesting a growing confidence in their ability to take interesting photographs and adopt photography as a way to communicate. It appeared, among all participants, that photography was bringing them a considerable amount of enjoyment and satisfaction.

Most collaborative meetings between the researcher and the participants were audio-recorded to assist in keeping detailed records of participant histories and lived experiences, except on rare occasions when participants requested private conversations. Additionally, field notes were written by the researcher after meetings to document the conversations and identify opportunities to

expand on topics in follow-up discussions. The field notes benefitted the collaboration by capturing the thoughts of the researcher after interviews and by allowing the researcher opportunities to review previous meetings and prepare for new meetings. The notes and pre-planning moved conversations toward deeper meaning and expanded opportunities to discuss wide-ranging issues that had been raised during previous meetings. Field notes were a valuable tool to remind the researcher about personal details that were learned from the participants.

4.7.2 Second Photo-sharing Meetings in New Haven

The second photo-sharing meetings were conducted in locations picked by the participants that were often much closer to their homes. These new meeting locations were a way of allowing the participants increased control, including when the meetings took place. This alteration of location strengthened the researcher-participant relationship and served to increase trust. The researcher benefitted by visiting the participants' neighborhoods to learn more about their lived experiences and the participants exhibited increased trust by inviting the researcher into their environments to personally see some of the cultural and social issues discussed in the conversations. When invited, it appeared that the participants were also assessing the researcher's willingness to visiting their neighborhoods. The trust-building actions in prior meetings established new connections, which led each interaction toward further improvements in communication. Each new meeting offered new possibilities to learn from the participants-as-experts, who often introduced new places, people and experiences to the researcher.

The changes in meeting locations were suggested by the researcher for the purpose of gaining a clearer understanding of each participant's ecological environment. Since all the participants lived within a three-mile radius of downtown New Haven, there were ample opportunities to meet at local social gathering places frequented by the participants. The second, third and fourth photo-sharing meetings occurred in locations ranging from local parks, coffee

shops and shopping districts, to the New Haven Free Public Library and Yale University Campus. Since only one New Haven participant had access to a car, the participants often walked to and from these meetings through their neighborhoods, met acquaintances along the routes and discussed landmarks or experiences introduced in previous conversations. When asked to walk and talk to expand the discussions, the researcher always agreed. These experiences and introductions provided the researcher with a deeper understanding of how the participants were viewed by and interacted with members of their neighborhood communities. The walking conversations occasionally passed through locations where participants described personal histories, past friendships and local culture. Walking conversations were not recorded but were referenced in the researcher's field notes and provided insight into the participant's perspectives of the neighborhoods and their social networks.

4.7.3 Additional Meetings in New Haven: Trust and Rapport

The weekly photo-sharing meetings were based on the availability of the participants and scheduling was prioritized to best meet their needs. Flexibility in scheduling based on the participants' needs improved the collaboration by increasing the length and frequency of meetings. Some participants asked for more meetings before the exit interview because they wanted to discuss photographs yet to be captured and those requests were accommodated by the researcher. Some participants missed meetings, which extended the collaborations by days or a week. As photo-sharing interviews were conducted, the participants over time, became more willing to deeply reflect on and explain issues introduced by the researcher in conversations. General issues discussed by the participants often led to follow-up questions with other participants to learn if there were similarities in perceived ideas without sacrificing anonymity and confidentiality. These questions led to meaningful discussions and common connections between participants' experiences, behaviors and perspectives.

After each collaborative meeting and conversation, the ability to ask more personal questions became easier and the answers more detailed. Although some personal stories were possibly exaggerated to reflect issues of strength, positive self-image and possibly to cultivate social capital with the researcher, each meeting made the research partnership stronger as the participants were continually more willing to tell their stories openly. The opportunities to ask deeper and more meaningful follow-up questions increased as the participants became more familiar with the investigation and confident in the researcher's willingness to learn from their personal experiences.

4.7.4 Exit Interviews in New Haven to Complete Stage One

After approximately four meetings with each participant to discuss their photographs, a final one-on-one exit interview was scheduled to culminate stage one of the research collaboration. Most commonly, the exit interview was scheduled at the centrally located New Haven Free Public Library. At the exit interview, each participant received printed copies of their color photographs to view and discuss, as well as a compact disc (CD) containing their entire photo collection. Each participant's images were used to guide the photo-elicitation exit interview. Each exit interview was audio-recorded and transcribed for inclusion. Most exit interviews lasted between 60-120 minutes.

The exit interviews were guided by the photographs chosen by the participants, and conversations varied widely in topic. Photographs that were identified by the participants as important or meaningful were separated from the collection and labeled for inclusion This process provided the researcher with a way to reduce the amount of overall submitted photographs into a smaller collection of photographer-selected images with their contexts understood by the researcher.

The exit interviews were instrumental in providing a clear interpretation of the content and context of the chosen photos. Often photos discussed in the exit interviews had different and/or multiple meanings from earlier descriptions during prior photo-sharing interviews. Some photos were associated with

surface content, while others were deeply subjective and had meaning beyond what was depicted in the visual frame.

The exit interviews served to make full use of the participants' expertise surrounding opioid use while making a direct connection to the content of the photographs. The images provided a place for researcher-participant connections, as well as a comfortable space to discuss associated memories and experiences. The photos were often used as representations of issues that extended beyond what was seen and often communicated ideas that reinforced the beliefs and perceptions of the photographers. The exit interviews fostered self-reflection among the participants and led to a deeper understanding of how the insidious nature of long-term opioid use affects all aspects of an individual's life.

At the end of each exit interview, participant photographers were given $70 (the US equivalent to £50) for their time and participation in the research project. At the conclusion of the stage one data collection period in New Haven, fourteen participants had been enrolled in the cohort and thirteen participants completed recorded exit interviews.

4.8 Recruitment and Enrollment in Liverpool

In preparing for the Liverpool-based investigation, the researcher compiled a list of substance use treatment organizations in the area that supported community outreach to people with drug use and housing needs. In an attempt to enroll a Liverpool cohort with similar demographics to the New Haven cohort, a search was conducted and local drug service workers were asked for their opinions on how to best recruit gatekeepers to then recruit older people who use drugs.

After discussions with local service providers, the researcher was able to partner with three local drug counseling services to collaborate with and recruit potential gatekeepers. After several weeks, four gatekeepers were recruited who introduced the researcher to thirteen participant photographers, each

meeting the inclusion criteria and were enrolled individually over the course of seven weeks in the Liverpool portion of the study.

4.8.1 Stage One: Participant-led Engagement in Liverpool

Enrollment meetings in Liverpool were conducted in the same format as the New Haven cohort, with gatekeepers on hand at the introductory meetings to discuss the project goals, risks and timeframe, as well as to represent the institutions involved in the study and protect the safety of the participants. The Liverpool gatekeepers signed written consent forms confirming their roles as participant advocates at the time participants agreed to participate and provided written consent for participation. Each enrolled participant was provided with a copy of the consent forms and was shown how to operate the loaned digital cameras and erase photographs using the camera's functions. The enrollment process, forms and inclusion criteria in Liverpool were the same as those used in New Haven.

After each Liverpool participant was enrolled, they were encouraged as those in New Haven, to set out and take pictures of subjects and circumstances they would like to discuss with the researcher at the next meeting. As in New Haven, there was no specific subject matter requested of the participants.

At the conclusion of each enrollment meeting, the researcher and participant scheduled a first photo-sharing meeting in one week as was done in New Haven.

4.8.2 First Photo-sharing Meetings in Liverpool

The UK participants all lived within four miles of Liverpool City Centre, with those farthest away identifying Sefton Park, Bootle and Everton as their home communities. Demographic data on the participants from Liverpool is included in *Appendix 4.* While Bootle is not technically in Liverpool, the three-mile distance from City Centre was in keeping with the same distances traveled by the participants in New Haven. The first meetings after enrollment took place

at the locations of our initial gatekeeper introductions to reconnect easily and begin the process of establishing the same level of trust and rapport as with the New Haven cohort. On a few occasions at the conclusion of our first meetings, the participants asked the researcher to join them to walk and chat after collecting and discussing their project photos.

The Liverpool participants had been informed that the first cohort in New Haven had been conducted with positive results. The Liverpool participants welcomed the researcher into their communities in a different way to those in New Haven. The researcher was a self-identified outsider with little experience of the cultural norms surrounding opioid use in the UK. From the start of data collection in Liverpool, there were clear cultural and social differences between the two international cohorts. The newly enrolled Liverpool participants appeared more willing to embrace the researcher and research, more comfortable with sharing personal details of long-term opioid use and more willing to engage in personal conversations about housing and relationships. They were less suspicious, less guarded and more friendly to the researcher than was the experience in New Haven.

In keeping with the structure and scheduling of the meetings conducted in New Haven, the first photo-sharing meetings in Liverpool were done at three local drug service locations. Each first photo-sharing meeting was an opportunity to collect photographs and discuss each participant's experiences with opioids. Many Liverpool participants remarked about their lack of confidence in their first photographs and their concern that the photographs may have been of poor quality. The researcher reassured the participants that their first photos were of good quality and were useful to discuss the associations with their personal lives and long-term opioid use. Nearly all Liverpool photo-sharing meetings were audio-recorded (excluding times when other people joined the conversations) and field notes were made after each collaborative discussion. As was the case in New Haven, walking conversations outdoors were not audio recorded.

4.8.3 Second Photo-sharing Meetings in Liverpool

The second photo-sharing meetings followed the same structure as was done in New Haven, with the participants choosing the meeting locations. At the second photo-sharing meetings, the participants were exhibiting more confidence in their photos and were more animated in their descriptions.

As was the experience in New Haven, each opportunity to share photos and discuss issues brought increased trust and the conversations became longer in duration. Often the topics stretched beyond the participants' photos and included the participants' perspectives of the generational differences between older and younger people who use drugs, the changes that have occurred in physical and mental health treatment over the last decade and how friends, family members and acquaintances have managed their own experiences with opioids. The participants' stories included more discussions of receiving multiple types of drug treatments for opioid use than the New Haven cohort. It appeared Liverpool participants had more experiences in receiving opportunities for detox and rehabilitation than those in New Haven. Some had been in detoxification and rehabilitation programs more than fifteen times.

4.8.4 Additional Meetings in Liverpool: Trust and Rapport

With the experiences of the New Haven cohort informing the collaborative partnerships in Liverpool, the conversations often encompassed issues of healthcare services, relationships, culture, drugs and local social problems. The researcher identified differences in the communication styles between the participants of each international location, with the American cohort quieter, more guarded and more reluctant to share experiences—even at times, introverted. The Liverpool cohort was friendlier, more talkative and appeared less stressed by the daily activities of life. In New Haven, the participants were invited to collaborate with the researcher in the research study, but in Liverpool, it was as if the invitation was mutual. The researcher felt more welcomed and was often invited to participate in small experiences, little extra

events that required planning and thoughtfulness by some participants. Most in the Liverpool cohort had steady jobs, a significant difference from the New Haven cohort, which rarely described consistent employment.

These differences may have been the result of the welcoming nature of the Liverpool community or the novelty of a foreign-born researcher asking questions about long-term drug use or possibly both. The New Haven cohort appeared to have greater stress, greater concerns about rooflessness and housing insecurity and more personal experiences with social isolation. This difference may have been related to the New Haven cohort's increased rates of rough sleeping, while the Liverpool cohort all had safe, consistent housing, including some in residential hostels. The cohorts were socially and culturally different for reasons unclear, but having a home was a universal characteristic in Liverpool, while all but three members of the New Haven cohort suffered insecure housing, homelessness or rooflessness on a regular basis.

The researcher's experiences in developing a trusting, participant-as-expert relationship among the New Haven cohort was beneficial in Liverpool, and the same methods were effective in generating new knowledge from the UK cohort. Every opportunity to engage with the participants was an opportunity for the foreign-born researcher to show respect and kindness to the Liverpool group. The intentional act of always giving the best chair to the participant at sit-down meetings was an easy, consistent approach to building a good rapport with each member. Seating can be a form of non-verbal communication and encompasses issues relating to power dynamics and social hierarchy (Riess and Rosenfeld, 1980). Empowering each participant through seating choices in private group settings was an important way to communicate respect through researcher behavior. Often this gesture, and the power dynamics it included, were identified by the participants in both cohorts, a latent signal of the researcher's respect for the individual and the collaborative partnership.

4.8.5 Exit Interviews in Liverpool to Complete Stage One

Exit interviews for the Liverpool cohort were done in many different locations to accommodate the participants' needs and busy schedules, with most conducted within the Liverpool City Centre area. All exit interviews were audio-recorded and field notes were written after the meetings. In a similar fashion to the exit interviews conducted in New Haven, each participant was provided with a collection of their self-made photographs to discuss along with a CD containing digital copies of all project photographs to take home. Each participant's images were used collectively to guide the photo-elicitation exit interviews. Exit interviews lasted on average between 60-120 minutes. All Liverpool participants were given £50 for their participation in the project at the end of the exit interview.

At the conclusion of the Liverpool data collection period, 12 participants completed exit interviews.

4.9 Moving from Stage One to Stage Two: The Transition from Participant-led Approach to Researcher-led Approach:

After finishing the last participant exit interviews, the data collection period for stage one of the *Modified Interpretive Engagement Framework* was completed. A total of 25 participants completed exit interviews and contributed photographs and narrative interviews to the collaborative study. All participants were informed at the exit interview that their thoughts and opinions would be invited by the researcher at a later date to confirm the overall findings of the study. All participants verbalized their satisfaction with the process and most expressed the desire to continue sharing photographs and stories about their drug use experiences.

Stage two of Interpretive Engagement began with the task of transcribing the audio recordings into written documents for both international cohorts, a task that was completed by the researcher over a two-month period.

Transcription was completed using naturalized transcription; whole sentences were captured with as many unspoken details as possible to represent a *real-world* approach to interpreting the speech without filtration of words by the transcriber or transcription process (Cameron, 2001). Transcription has deep roots in qualitative research to provide evidence about events and experiences that relate to phenomena under investigation (Duranti, 2006). The act of transcription may be influenced by cultural characteristics, institutional and academic environments, and the background of the researcher and transcriber, which affirm that reflexivity is a beneficial and inherent component of a rigorous and trustworthy transcription process (Bucholtz, 2000).

In this study, transcription was conducted by the researcher who also conducted the interviews, which brought a level of subjective representation to the process while also bringing an objective understanding of the participants as a whole. Transcription by the researcher was a benefit in this study as the researcher was uniquely suited to conduct naturalistic transcription of the interviews through his research experience, knowledge of the participants' lives, emic perspective and personal connection to each participant. Transcription by the researcher reduced the chance for inconsistencies, prevented the omission of conversations and maintained a connection to symbolism and nonverbal communication by the participants, as the researcher experienced the interviews as they were recorded.

4.10 Stage Two: Researcher-led Engagement and Analysis

Stage two of *Interpretive Engagement* began with the collection of all the research materials: the interview transcripts, the participants' photographs and the researcher's field notes. Having personally completed the transcription of the interviews, the researcher had a clear and detailed understanding of the perspectives and opinions of the research participants.

A criticism of qualitative analysis holds that a sole researcher as transcriber may not provide a trustworthy analysis alone and should instead be accompanied by additional researchers to prevent errors in transcription and

strive for consensus in analysis when appropriate (Rodham, Fox and Doran, 2015). In this study, the researcher was uniquely positioned to conduct the investigation alone. The methodological framework used in this study positioned him at the center of the visual research universe; centralized among twenty-five orbiting lived experiences, each a socioecological environment of cultural beliefs, personal perceptions and social behaviors.

The researcher spent a significant period reflecting on the perspectives of the participants as well as the subjects and experiences discussed during the collaborative process. The participants' stories were interesting, and although their words were easily transferrable to paper, what posed greater difficulty to convey in the transcripts was the laughter, crying and emotional pauses that furthered the researcher's understanding. The shared experiences between the researcher and the participants added knowledge about cultural, social and environmental complexities would not have been discovered through more traditional qualitative analyses. Both the words and the emotions of the participants were equally important in collecting the stories of opioid use among the cohorts. The latent, non-verbal forms of communication remained in the memories and field notes of the researcher and were important factors that reinforced the deeper meanings behind many of the issues discussed.

When conducting data analysis, the researcher becomes an instrument for making judgements and decisions about categorization, theming and decontextualizing/recontextualizing of the data (Starks and Trinidad, 2007). Each process follows certain ethical and systematic techniques for analysis, but the responsibility of assuring rigor and trustworthiness belongs to the researcher (Guba, 1981). Credibility is dependent on the transparency of the process and the researcher's ability to record, categorize and detail the process of moving from the collected data to research findings (Johnson Adkins and Chauvin, 2020).

Stage two of the *Modified Interpretive Engagement Framework* used Attride-Sterling's Thematic Networks Analysis, a step-by-step technique for conducting a thematic analysis of qualitative material after unsuccessful

attempts to use two different qualitative data analysis software programs. The final thematic method employed an established, well-known technique and was used to develop a visual map of thematic networks; interconnected associations and categories built upon the participants' own words. Thematic Networks are web-like illustrations that summarize the main themes, which represent original participant quotes. The Thematic Networks technique is a robust and responsive tool for the systematization and presentation of qualitative analyses (Attride-Stirling, 2001).

4.10.1 Thematic Networks Analysis: A Process

Prior to adopting Thematic Networks Analysis for this study, the researcher began the analysis of the data using two different qualitative data analysis software programs: first MAXQDA, then NVIVO11. During this period of analysis, the transcripts were coded using several different techniques including, in-vivo coding, action/process coding, open coding and concept coding. Each of these methods of coding was used to compile categories in MAXQDA and NVIVO11. Upon completion, the codes were evaluated for their accuracy, association and ability to lead the researcher to the development of high-level themes.

While the use of data analysis software provided an organized and systematic way to categorize the experiences, perceptions and behaviors of the participants using nested nodes (codes), the researcher felt that the emotional, deep meaning between the participants' words and the development of software hierarchies was lost. The data analysis software seemed impersonal and detached from the significance of the participants' words. It became increasingly difficult to maintain a direct connection between the participants' words and the development of higher-level themes, so a new method of thematic analysis was undertaken.

After restarting the analysis of the interview data twice using data analysis software, the researcher chose Thematic Networks Analysis as a superior method which benefitted from the researcher's position within the data

collection process. Thematic analysis allowed for the researcher's emic perspective and understanding to inform decisions about which participant quotes to include in a way that content analysis does not.

TNA is a systematic process that incorporates more meaningful data than the alternative process of content-coding the phrases and sentences selected from transcripts (St. Pierre and Jackson, 2014). TNA includes researcher field notes, reflections, recollections and reflexivity in conjunction with the meanings of the participant photographs and their associated narratives, which separates thematic analysis from content analysis. The process of thematic analysis in this study did not specifically include the photographs as visual data, however, it did include the researcher's interpretations of the meanings and experiences that were conveyed through the participants' photographs and descriptions. The process of thematic analysis took weeks of categorization and re-categorization, slowly developing *basic themes* from the participant's own words and moving systematically through re-categorization toward higher-level themes.

The original, hand-drawn Thematic Network Analysis, available in *Appendix 3,* is a photograph of the original TNA map. The *Thematic Networks Analysis Infographic* (p.95) was developed on a foundation that used participant quotes, participant descriptions and field notes which pertained to the photos and their meanings. Originating from the narrative data, participant quotes were chosen using concept coding, a way of identifying short phrases and comments that represent a meaning broader than a single item or action (Saldana, 2014). Concept coding focuses on ideas rather than objects or observable behaviors, an important foundational choice that allowed participant actions and behaviors which were grounded in *ideas*, to form the basis of thematic analysis (Nowell and Norris, 2017).

Using concept coding, 200 quotes about ideas, motivating factors and life circumstances which connected those ideas directly or indirectly to opioid use, were included to form the basis for the thematic analysis. Also, quotes pertaining to ideas surrounding health, life-altering experiences, and social

relationships were included. Repetitive topics from multiple participants were not given higher priority nor were they used to inform decisions about what themes should evolve from the data.

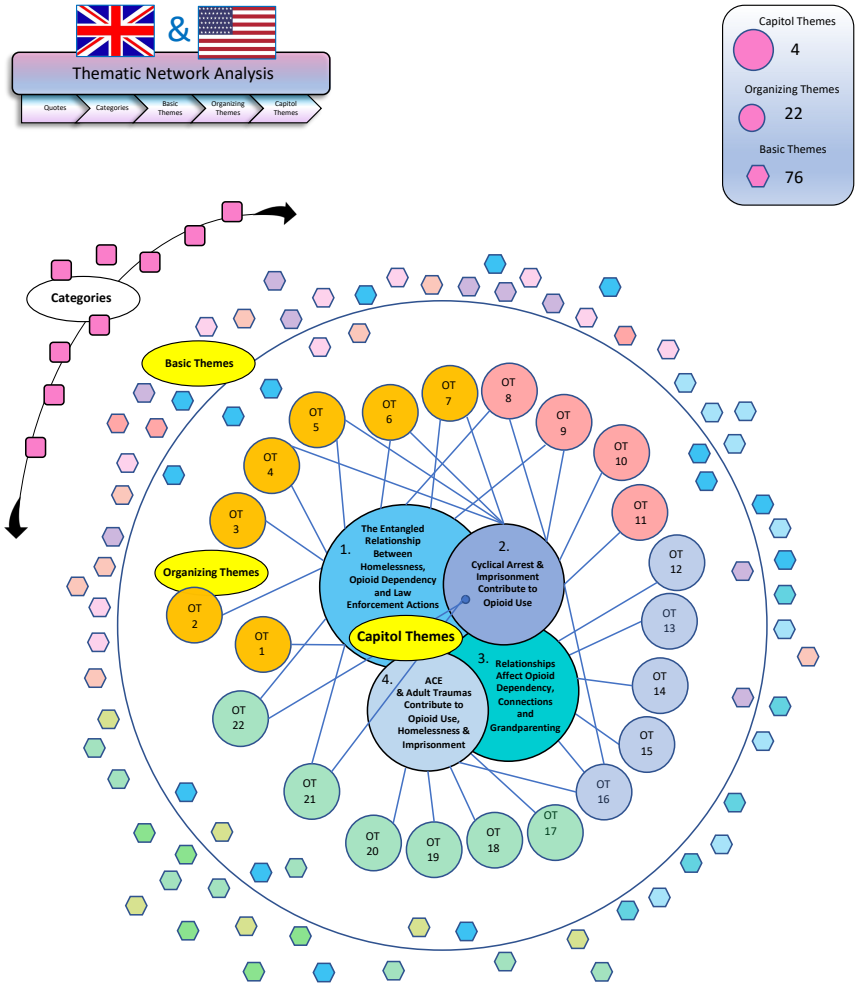


Figure 2. Thematic Network Analysis Infographic

From 200 quotes, a multitude of interconnected categories were developed from which several *lowest-level themes* emerged. In this research study, lowest-level themes are referred to as *basic themes* and were developed as

an early step toward beginning the process of organization through categorization. *Basic themes* are described by Attride-Sterling as, “simple premises characteristic of the data, but do not offer a perspective of the data as a whole” (2001, p.389). As *basic themes* were developed, refined, categorized and recategorized, newer, middle-level themes began to emerge from similarities and commonalities revealed in the formulation of lower-level themes (Attride-Sterling, 2001). Middle-level themes were developed from the *basic themes* and formally labeled as *organizing themes*, which served to summarize more distinct principles than the lower-level *basic themes.* A list of the 22 *organizing themes* from this research is available in *Appendix 2.*

O*rganizing themes* were systematically categorized and recategorized to develop super-ordinate themes which encapsulated issues and the predominant ideas of the participants. Super-ordinate themes were developed by using both the *organizing themes* and the visual web of networked connections that attached each *organizing theme* directly to its lower-level *basic themes* and quotes (Attride-Sterling, 2001. This process of super-ordinate theme development, as Attride-Sterling explains, “makes sense of clusters of lower-order themes that grew from and were supported by the participants’ own words” (2001, p.389). Super-ordinate themes are referred to as *Capitol Themes, which* inform the reader about the texts as a whole and accurately summarize the main themes to reveal a systematic interpretation of the interview data. *Capitol Themes* can be traced back through the web-like network analysis to identify from how they were developed according to their lower-level *organizing themes* and how those *organizing themes* were predicated on the careful and systematic development of *basic themes* which grew out of the narrative data (Attride-Sterling, 2001). The ability to re-trace connections between *Capitol Themes* and participant quotes is available using the original thematic networks analysis map, in *Appendix 3.*

Although *Thematic Networks Analysis* does not include photographs as visual data, the process stands as a rigorous and trustworthy method of determining research findings from PGIE and photo-documentation. The TNA infographic map (p.95) depicts a clearer version of findings from *Thematic Network*

Analysis and serves as a secondary guide to ensure a clear understanding of the technique. As previously stated, a list of the 22 lower-order themes which led to the development of *Capitol Themes* is available in *Appendix 2*.

To maintain a direct association between the *Capitol Themes* and the final selected images, only photographs with content associated with the 200 quotes were selected for inclusion to accurately align the images with the findings from thematic analysis. All research photographs were submitted for inclusion by the participants; it was not necessary to subject the images to a particular thematic process of qualification and/or elimination before finalizing the *Capitol Themes*. Participant photos, narratives and experiences were systematically analyzed after the development of *Capitol Themes* to create *Capitol Works,* thirty-two visual images that detail the most important issues discussed by the participants and include associated participant quotes and personal descriptions.

A major factor in choosing and using TNA in this research was to systematically develop a hierarchy of themes while maintaining a distinct and identifiable connection to both the narratives and the participants' selected photographs. The resulting *Thematic Networks Analysis Map* (*Appendix 3***)** succeeded in the development of a visual, retraceable map that links the systematic processes through their attributable pathways from interview data through superordinate theme development.

The TNA began with 200 quotes and developed 76 *basic themes*, which contributed to the development of 22 higher order, *organizing themes,* which supported the emergence of four highest-level or super-ordinate, *Capitol Themes*. The *Capitol Themes* encapsulate the predominant issues identified within the narrative data and provide a basis upon which participants' photographs can be selected to best exemplify the themes.

4.10.2 Photographic Analysis: New Haven

The photographs represented factual data and were sorted by their visual quality, theme and meaning by each participant photographer. The photographs were submitted and discussed by the participant photographers on a meeting-by-meeting basis. An album of photographs was created for each individual participant photographer and additionally for each cohort, beginning with the first participant submissions to provide a tangible visual record of the ideas, subjects and concerns each group shared. The albums served as a diverse visual record that grew weekly with each collaborative encounter. The album of photographs was not shared with the participants however, the meaning and content of the album's photos was a frequent general subject that the researcher used to connect the participants to one another's stories and convey the ideas of the community-based participatory collaboration.

Maintaining photographs in digital files allowed for safe storage and a filing system with two folders for each participant. One folder held all of the participants' digital photos and another folder held participants' *favorite* photos. Favorites folders were the source for the cohort photo albums. Favorites folders were adjustable and changeable; they were added to, switched around and replaced occasionally with new favorites after meetings. The photo-sharing interviews led to lively discussions about visual research. The photographs provided the perfect mechanism for developing deeper connections between the researcher and the participant photographers. The photos served to increase communication through a shared appreciation for art and learning, which broadly expanded the range of subjects open for discussion.

At the end of the New Haven data collection period, the album of cohort *favorite*s totaled 70, averaging slightly more than five photos per participant photographer.

4.10.3 Photographic Analysis: Liverpool

The method of collecting participant photographs in Liverpool remained the same as in New Haven; images were secured on a meeting-by-meeting basis on the researcher's laptop, and an album of cohort *favorites* was created for the researcher's benefit. The most meaningful and interesting images submitted by the photographers were discussed at each meeting, and the cohort album grew larger and more subjective over the course of the collaboration.

At the end of the Liverpool data collection period, the album of favorites totaled 66, averaging five and a half photos per participant photographer. Although the majority of the images never made it into the *favorites* album, each photograph contributed to the general discussions and the development of research findings.

4.10.4 Connecting Photographs to Capitol Themes

The two cohort albums (66 UK images and 70 US images) were re-examined to identify which of the 136 images best exampled interesting and meaningful photographs and contained a direct or indirect association with the four *Capitol Themes.* A two-person selection process was used to reduce each cohort's total photographs to 16 final images, a way of ensuring an accurate and trustworthy relationship between the individual cohort's images and the findings of the thematic analysis. A two-person selection process was conducted by two researchers: the author and a healthcare practitioner with experience in accessing the social needs of families and individuals in the New Haven area with experience in photovoice methods.

The photograph selection process began with each cohort's photo collection. Photographs that did not have a direct or indirect association with the four *Capitol Themes* were removed. The two-person selection process used two basic criteria to remove pictures from the cohort photo collection: (a) would an audience member recognize an association between the photo and the

photo's meaning through the addition of the participant's words and (b) does the photo, it's meaning and the participant's words bring an audience member to a greater understanding of long-term opioid use.

After the selection process was completed, the respective collections were searched for visual repetition and those images found to be exceedingly similar were removed until the last 16 images remained. After the collection was rechecked, the photographs for inclusion were confirmed as 16 images from the New Haven cohort and 16 images from the Liverpool cohort, with each photo having a direct or indirect association with one or more *Capitol Themes.*

4.11 Substance Use by Participants in Liverpool and New Haven

Substances used prior to and during the collaborative process had an effect on the experiences shared with the researcher. Frequently, over the days and weeks of interviews, the participants shared their experiences with polydrug use, their historical quests for drugs often to remedy *dopesickness* and the need to substitute and/or combine different illicit drugs to satisfy their needs.

The New Haven cohort of 13 people all had long-term experience with opioids, most beginning with prescription pain medications and transferring over time to less expensive forms of smokable and injectable powdered heroin when prescription opioids became too difficult or too costly to obtain. Four of the New Haven participants were using heroin or prescription opioids during the five-week interview process. All participants verbalized the past use of alcohol both socially and to keep warm when sleeping outside in cold weather, however some participants were proud to describe their more recent adherence to an alcohol-free and drug-free lifestyle, a result of their associations with Alcoholics Anonymous (AA) and Narcotics Anonymous (NA). All four veterans were active members of the West Haven VA AA group and attended meetings frequently, often daily if transportation to and from the West Haven Campus was available.

While there were no requirements for the participants to list all the drugs they had used over their lifetimes, ten New Haven participants described long-term use of cocaine or crack and all participants used marijuana at times when they smoked cigarettes. Seven New Haven participants described their experiences selling illicit drugs and two described accepting prescription medications such as Xanax, Ritalin and HIV medications in trade for heroin and cocaine. The researcher is aware of the availability and resale of prescription HIV antiviral medications, methadone, buprenorphine, diazepam and methylphenidate on the New Haven Green, but cannot be certain of the exact drugs sold by the participant entrepreneurs.

The Liverpool cohort of twelve people all had long-term experience with opioids, all beginning with an introduction to brown powdered or black tar heroin in early adulthood by peers, friends and intimate partners. Nearly all participants began heroin use through smoking the drug in Liverpool, although two people disliked smoking heroin and chose to inject early in their drug use careers to improve the euphoric effectiveness of heroin. No participants in the Liverpool cohort became drug dependent on prescription pain relievers, however all self-described themselves as opioid dependent. Six Liverpool participants described the long-term use of methadone scripts and believed their personal use of methadone, prescribed by a GP, contributed to problematic opioid dependency. Some participants used methadone scripts continuously for over a decade.

Alcohol use among the Liverpool participants was universal prior to many adhering to AA and NA supported abstinence goals. Diverted prescription opioids were not identified by Liverpool participants as a gateway drug to illicit heroin as was the case in New Haven. Two Liverpool participants who continue to use opioids regularly described recent experiences with poor quality powdered heroin and remarked that they needed more than one bag to achieve their desired effect. One participant said they required a bag of cocaine whenever they purchased a bag of heroin, because they could never inject one illicit drug without the other due to the consistently poor drug quality and increasing their overall risk of overdose.

Other drugs used by the participants in the Liverpool included cannabis, synthetic cannabinoids, cocaine, methamphetamine, GHB and MDMA. Five Liverpool participants talked about having a long history of selling illicit drugs for profit. One Liverpool participant explained his/her continued participation in the lucrative cannabis trade and envisions his/her future in the legalized distribution of cannabis as the laws governing sale in other countries may change. Six participants from the Liverpool cohort regularly attend AA and NA meetings and consider themselves 100% drug and alcohol free.

4.12 Diversion and the Use of Prescribed Drugs to Secure Illicit Drugs

Differences in the availability of diverted prescription opioids in the US and UK were stark when examining how legal drugs enter illicit markets. While anecdotal evidence suggested this may happen in the UK to a lesser extent, participants in New Haven explained specifically how prescription medications can be used to trade for illicit drugs or quickly sold for cash.

As discussed in depth by the New Haven participants who received health benefits from the VA, prescription opioid medications can be used for more than the alleviation of pain symptoms. Commonly, opioid prescriptions for chronic pain conservatively use a daily dose of five to twenty milligrams, three to four times per day. Ninety-day prescriptions, which are no longer legally written by prescribers in CT as of 2019, could range from a total of four hundred sixty-five milligrams to twenty-four hundred milligrams of opioid pills. In New Haven, as in other US cities, diverted prescription opioid pills are worth approximately one to two dollars per milligram, making a 5 mg tablet worth approximately five to ten US dollars, and a monthly prescription worth between $700 - $2,500. New state guidelines in CT prevent the prescribing of more than seven days of opioid medication at one time, which effectively reduced the illicit supply and reduced overall exchanges between opioid buyers and sellers.

The VA recognized the powerful incentive to divert opioids for profit and the diversion of prescription opioids from any medical professional continues to be illegal and punishable by law. To this end, the VA has instituted “pain-contracts” since 2011, which address in writing what is to be expected of the client seeking pain treatment as well as the pain doctor’s goals. Pain-contracts adhere to a strict schedule and are based on the consistent use of opioid medication as directed. As indicated in the VA pain-contracts, patients may be tested at any time to ascertain the level of opioids in their systems. If a veteran’s normally expected level of opioids in his/her system is found to be too high or too low, the pain contract can be nullified by the doctor and opioid pain medications will be discontinued permanently, giving the doctor an opportunity to end the doctor-patient relationship due to drug misuse. 3 New Haven participants spoke of the forced-nullification of their pain-contracts because of rising opioid tolerance and the need to take opioid medications at a faster rate than specified by the prescribing doctor. No New Haven participants admitted to profiting financially from their opioid prescriptions, but spoke of knowing people who did. Stories about these people revealed that some individuals save only enough opioid pills to maintain the appropriate level of drugs in their system when going in for drug testing once every ninety days and sell the rest of their prescription medications to supplement their income, a risk some are willing to take due to the high profit margin in selling prescription opioids into the street market economy.

Pain contracts are a valuable tool for both doctors and patients, but economic hardship can force a person with few financial options to divert opioids for profit. Veterans who diverted their medications did so for different reasons. Some did not have debilitating chronic pain and diverted their medications to make money. Some diverted their medication while continuing to have pain, but chose to accept the physical discomfort in order to profit from the resale value of opioids. Some sold their prescription opioids and bought less expensive heroin and pocketed the difference. Some veterans were known to trade other medications like Diazepam, Buprenorphine and Adderall for heroin while on the VA campus engaged in AA or NA meetings.

The diversion of prescription drugs opioids was not limited to those with VA health benefits, as doctor shopping for opioid prescriptions in the US was identified in the literature as one of the most common ways prescription opioids migrated from medical to recreational use between 2001-2011, before federal changes to the distribution of opioids curtailed some illicit trade. Federal implementation of the Prescription Drug Monitoring Programs (PDMP) was implemented in 49 of 50 states and the District of Columbia (DC) as a way to search for evidence of over-prescription by prescribers and over-consumption of prescription opioids by individuals.

4.13 Ethnicity and Race of the Participants

The impact of opioid dependence is evident across all demographic groups however, some demographic differences existed when comparing opioid use by race and ethnicity in New Haven and Liverpool. According to the National Institutes of Health (NIH), white Americans, those who can trace their ancestry to Europe, the Middle East and North Africa, experienced the highest rates of opioid misuse and death from opioid overdose. In the UK, where rates of opioid dependence and misuse are significantly lower than in the US and where approximately 86 percent of the population is white, overall rates of opioid related poisonings and opioid related deaths were found to disproportionately affect white populations, similar to what has been identified in the US. Statistically, while white people use opioids in greater numbers than other ethnicities, black and brown people are disproportionately impacted by institutional racism and entrenched discrimination in addition to the stigma of being opioid dependent.

Unlike the Liverpool cohort, who all received health care through the NHS, four New Haven participants had no access to healthcare and six had no access to stable housing. All African American and Latino New Haven participants described mistreatment by law enforcement and experienced arrest and imprisonment as a form of punishment for being homeless. The African American and Latino New Haven participants described experiences where

the attitudes and behaviors of those in power were used to discriminate and exclude them from accessing services. The participants experienced episodes of prejudice, ignorance and intolerance that directly impacted them and stereotyped them as homeless drug users. Black and brown participants from New Haven believed racism and discrimination made entry into shelters, interactions with law enforcement and economic hardship more difficult than it was for white participants.

The experiences of the nine African American and two Latino participants from New Haven were significantly different from the two white participants. This dual problem of racism combined with the stigma of drug dependence, has resulted in local New Haven organizations failing to provide professional services to participants because of their color, culture, lifestyle and ethnic origin. This type of racism was described as a societal problem and was found embedded within the local institutions that were originally designed to assist all low-income community members equally. Racism and discrimination contributed to housing problems and obstructed individuals and their families from accessing shelter beds and temporary housing. Participants indicated that this type of discrimination extended to interactions with local police, health practitioners, food pantries and housing providers throughout New Haven.

Institutional racism refers to a form of racism that is ingrained in the laws, regulations and historical design of a society and discriminates against a particular group, resulting in inequalities in education, employment, criminal justice, housing, health care and political representation. Institutional racism exists in New Haven and contributes to the environmental conditions that complicate the lives of people who use opioids, particularly people of color.

The eleven black and brown participants described experiences of inequality in housing opportunities, lost job opportunities, inaccessibility to healthcare services, physical altercations with law enforcement and episodes of imprisonment. For eleven of thirteen participants from New Haven, race and ethnicity were major factors in their personal lives and ecological environments. They endured chronic discrimination in both subtle and overt

ways, often resulting in disadvantage. This was not the same experience of the twelve white Liverpool participants, nor the experience of the two white participants from New Haven. White participants suffered hardships, but institutional racism redoubled the difficulties of stigmatized and marginalized drug users and often made solutions impossible to obtain.

4.14 Stage Three: Recontextualization among Participants

Stage three of the *Modified Interpretive Engagement Framework* altered Drew and Guillemin's original framework from audience checking to member checking to maintain trustworthiness and confirm participant safety measures. As detailed previously in this chapter, the written consent forms allowed for the photographs and narrative data to be shared among the participants and other researchers. The 32 final images, along with the findings from the thematic analysis and the associated participant quotes were compiled in an eight-minute photo collection video that was shared with the available participants as a way of member-checking the results with the available collaborating photographers. The photo collection was created to show the photographs in the context of a collaborative partnership, displaying for the first time to the available participants, the collection of images from Liverpool and New Haven together.

The collection was categorized by international location and the photographs were accompanied by quotes to strengthen and support the messages and meanings. This method served to inform the participants of how the other members viewed their lives and what meanings the other photographers used to describe their ideas and experiences. The images used in the collection of 32 photos were labeled by country of origin to provide social and cultural context to the participant viewers.

After viewing the photo collection once using the research laptop, the participants were asked their opinions of the findings with one simple question:

"Do the photographs and Capitol Themes accurately reflect your lived

experiences and do the Capitol Themes capture the most significant problems facing older people who use opioids?"

The participants who viewed the collection were unanimous in their full support of the research findings. The participants appreciated the opportunity to confirm the results and felt that they contributed to a trustworthy research investigation. This was the participants' first and only opportunity to experience the project as a collaboration recognizing the work of other participant-photographers and the first moment to feel a connectedness to others in the study. Most member-checking conversations focused on problematic interpersonal and community-based issues and their associations with long-term opioid use. No participants suggested needed changes among the findings, nor overlooked issues, nor the inappropriateness of any images selected for inclusion.

Stage three: recontextualization increased the study's trustworthiness by confirming the results with the participants and by developing those results through the use of a rigorous and systematic process. The recontextualization stage also brought a clear conclusion and a sense of purpose to the collaborators after a long wait, as the exit interviews were conducted many months prior to stage three. The participants had willingly worked independently with the researcher and trusted that their work would contribute to a greater whole. The opportunity for member-checking allowed the researcher to reconnect with the participants on an individual level and provide them with recognition for their contributions to the public health research project.

4.15 Limitations to Stage Three: Recontextualization

Stage three: recontextualization had limitations in member checking as many of the participants were living under conditions of housing instability and were using drugs when they enrolled to participate in the study. Although each participant was introduced to the project by a local gatekeeper and had a working cell phone when the project began, there was difficulty in reconnecting

with many of the participants after months of disconnection from the project. Most of the participants were no longer reachable at the phone numbers provided at enrollment.

Gatekeepers explained this lost connection as a consequence of homelessness, a result caused by the same conditions that contributed to the research findings. Of the twenty-five participants who took pictures and completed exit interviews, only nine saw the photographic presentation and provided personal opinions of the findings. The lost connections to the participants were a significant additional finding which further supported the *Capitol Themes* and confirmed the existence of social, economic and structural problems that complicate problematic long-term opioid use and accessibility to treatments available to this population.

4.16 Chapter Summary

The methodological choices described in this chapter were used to construct two community-based participatory research investigations among older people who use opioids and compared the data between cohorts. Two forms of data—participant-generated photos and participant interviews—were collected and analyzed, resulting in a collection of photos representing themes identified by discussing participant-made photographs with the participants who made them. The results of the Modified Interpretive Engagement Framework identified 32 selected photos with accompanying quotes which represent the greatest issues of concern among both cohorts.

The investigation also led the researcher to a deep and detailed understanding of how racism and discrimination affected the black and brown participants disproportionately to the white participants. Being uniquely positioned at the center of the research study provided the researcher a unique vantage point from which to explain the differences in the experiences of the participants by race.

Chapter 5: Research Findings Through Use of Words, Photographs and Experiences of Older People Who Use Opioids

"At the root of creativity is an impulse to understand, to make sense of random and often unrelated details. For me, photography provides an intersection of time, space, light, and emotional stance. One needs to be still enough, observant enough, and aware enough to recognize the life of the materials and to be able to 'hear through the eyes." - Paul Caponigro.

5.1 Introduction

This chapter introduces the reader to the results extracted from the three-stage Modified Interpretive Engagement Framework (MIEF). The findings from the MIEF are *Four Capitol Themes* and *Thirty-two Capitol Works*, which were developed through the use of participant photographs, narratives and experiences. To systematically develop the findings, three analyses were completed. The following infographic was designed as a visual roadmap to guide the reader through the design and implementation of the MIEF.

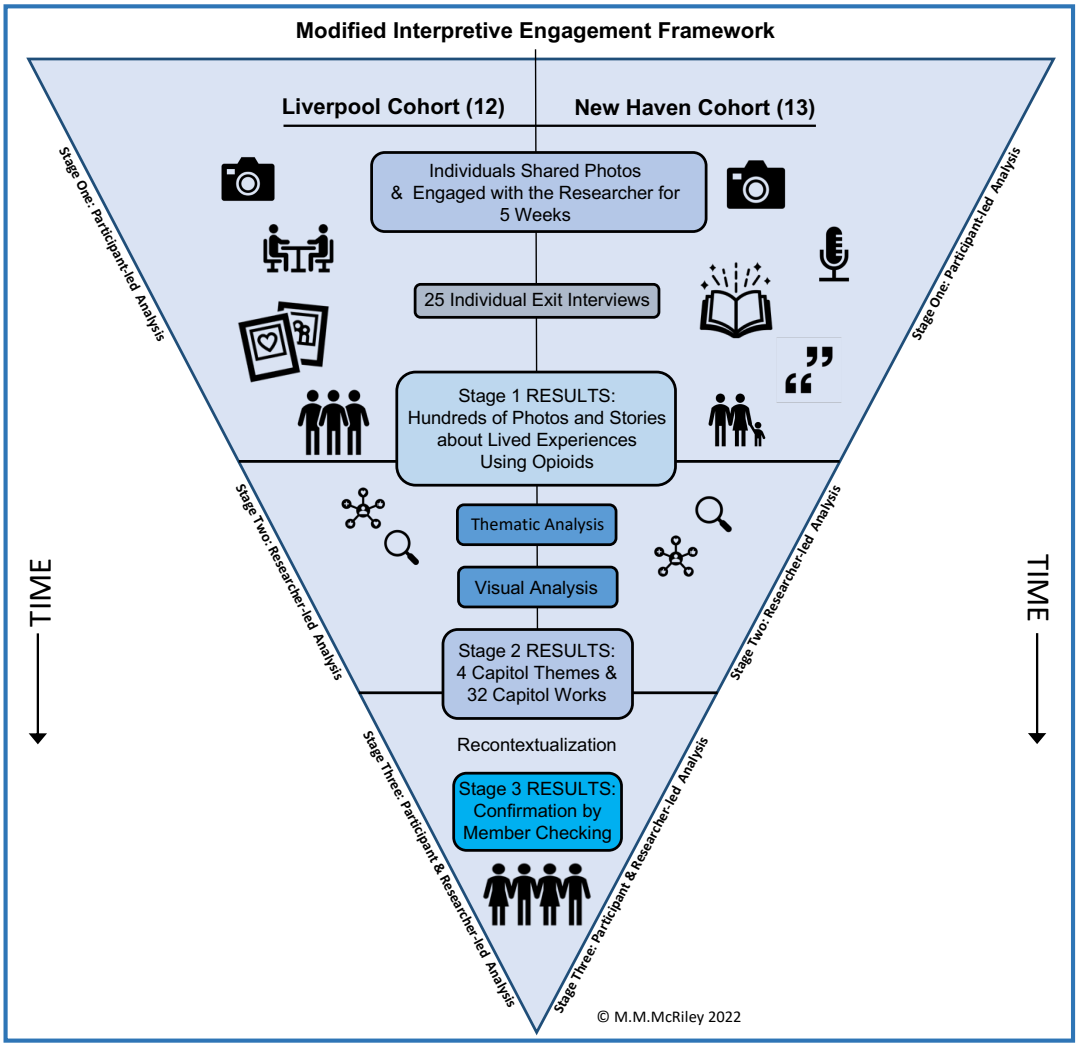


Figure 3. Modified Interpretive Engagement Framework

The following represent 3 analyses.

- Within the MIEF, a *thematic analysis* was conducted using the interview data from twenty-five participants. Four *Capitol Themes* resulted from the analysis of their stories, photograph meanings and experiences.

- Within the MIEF, *a visual analysis* was conducted of the photographs and their meanings and contexts from twenty-five participants. Thirty-two *Capitol Works* resulted from the analysis of their stories, photographs and experiences, which support the four *Capitol Themes*.

- Lastly, the results of the *thematic analysis* and the *visual analysis* were member-checked by participant photographers to confirm the associations between the thematic analysis results and visual analysis results with the participants' lived experiences of long-term opioid use.

This chapter presents the four *Capitol Themes* and thirty-two *Capitol Works* as findings from the systematic analytical processes. The superordinate themes and works are referred to as *Capitol* because they are structural in nature, house important ideas and principles, ethically represent the people of a particular society and support equity, equality and human rights. Additionally, this chapter presents details regarding an association between difficult-to-capture photographic subjects and the participants' willingness to discuss critical hardships, homelessness and relationships.

5.2 The Use of Thematic Analysis and Visual Analysis to Develop Findings

To aid the reader in understanding the systematic process of TNA within the MIEF and how the thematic analysis was undertaken, an infographic was included (p.95) to provide a visual road map and assist the reader in moving forward and backward through the analysis of the narrative data.

The *visual analysis* of the participant photographs was conducted using a modified version of the peer-reviewed framework developed by Drew and Guillemin (2014). As presented in 5.1, the infographic, Modified Interpretive Engagement Framework was included to provide a visual roadmap of the systematic process, which includes the development of both narrative and visual findings.

Included below are 5 infographics which combine the *Capitol Themes* with the *Capitol Works* to provide the reader with a visual road map to better understand the associations between the *Capitol Themes* and the participants' photographs and narratives. While the following infographics contains thirty-two images which represent the *Capitol Works*, the *Capitol Works* have deeper

meaning and are the result of a *union between images, narratives and experiences of the participants* and are not intended to be sole images without descriptions as depicted in the following infographics. The full versions of the thirty-two *Capitol Works* can be found in section 5.7. The following infographic is all four Capitol Themes and all 32 Capitol Works together for the reader.

Figure 4. All Capitol Themes and Capitol Works

5.3 Theme One

The Entangled Relationship Between Homelessness, Opioid Dependency and Law Enforcement Actions

Figure 5. Capitol Theme One and Associated Capitol Works

Broad homelessness remained a consistent and significant problem in both Liverpool and New Haven, a consequence of a combination of factors including: the availability of illicit drugs, problematic illicit drug use, economic instability, joblessness, fractured relationships, critical hardships, traumatic life experiences, cyclical imprisonment and participation in criminalized activities. Rooflessness, couch-surfing, rough sleeping and housing instability were

found to contribute to problematic drug and alcohol use, adult traumas, arrest by law enforcement, hopelessness, social isolation and risk for suicide. The conditions of broad homelessness existed among older people who used opioids in Liverpool and New Haven and were positively associated with the frequency of law enforcement interactions. Healthcare services and drug treatment opportunities were less available and more difficult to access in New Haven than Liverpool and often failed to adequately address and remedy the complex issues surrounding the triad of broad homelessness, physical and mental health needs and opioid dependence.

Twenty-six of thirty-two Capitol Works (81%) were associated with the theme of the entangled relationship between homelessness, opioid dependency and law enforcement actions. This triad, described in detail by nearly all the participants in New Haven and Liverpool, is a complex and often dynamic consequence of multiple factors affecting daily life. Broad homelessness was reported by the participants as one of the most common and pressing concerns for older people with long-term opioid dependency, as rough sleepers in Liverpool and New Haven are ubiquitous and strongly associated with problematic long-term drug use, alcohol use and mental health issues. Risk of eviction and by extension broad homelessness, remain a potential reality for long-term opioid dependent individuals who rent housing or receive governmental housing support, which includes twenty-four of twenty-five (96%) participants. Community members in both Liverpool and New Haven witnessed rough sleepers and homeless encampments on a daily basis in each community which kept the association between opioid and alcohol dependence and homelessness in the minds of those at risk for similar outcomes. Participant images of rough sleepers and the conditions of broad homelessness were extremely common among all the photographers. Twenty-one of twenty-five (84%) participants experienced simultaneous periods of rooflessness and opioid dependency and thirteen of twenty-five participants (52%) experienced rough sleeping during periods of opioid dependency.

"I was called a junkie, you see, indignities happen to rough sleepers. I've been urinated on, I've been beat up, Christ, I've been sent to the hospital bloodied. I've got four folders from the hospital, records of my injuries. I've had kids jumping on me head for big laughs, they stopped the car before running me over, and I tried to keep walking, but then I felt a smash on me head, and I heard them laughing and say, oh he's only a smackhead anyway." Where's the understanding? Where is the empathy? It's the culture of Liverpool, you're not going to get rid of homelessness in City Centre because everybody makes their money there to survive. That's why 9 out of 10 who do hard drugs are shoplifting or robbing cars, they're not living in doorways. Living in a doorway is an indignity and the bottom and there is no easy fix for it. […] I'm quite passionate about homelessness because I have suffered it. I lived beside the pyramid in the cemetery on Rodney Street for 3 months." (DN, UK)

As described by participants in New Haven, the number of housing placements for homeless individuals seeking assistance did not meet the current demand and have resulted in a system-wide failure to adequately accommodate homeless individuals, particularly homeless men. While anecdotal evidence in New Haven suggested women with children and women escaping physical abuse received priority placement in local, temporary non-governmental housing, rising demand on housing placement programs have extended the length of time the average homeless man waited for safe and affordable housing in New Haven, from several months to years, which left few alternatives to continuing the pursuit of illicit drugs to avoid withdrawal symptoms, living in unstable housing, participating in criminal activity and as a result, repeated interactions with law enforcement and risk for arrest.

Housing placements in Liverpool shared similarities with those in New Haven, where temporary housing shelters were serving more frequently as short-term housing placements, due to limited availability, austerity measures and rising population needs. Liverpool's rough sleeping initiative, No Second Night Out, did provide shelter to those seeking assistance, but did not necessarily provide a bed or extended stay. Shelter in Liverpool was considered protection from

outdoor conditions and at two local facilities the researcher visited, there was a place to sit safely inside and access to clean bathroom facilities, but there were no beds, no consistent free meals, nor were pets allowed into the facilities, which prevented homeless individuals with dogs from accessing even short-term shelter services.

"I was proper worried. I was out looking for them, and I went and found them. But I don't know where they are going to sleep tonight (in Liverpool City Centre) and it breaks my fucking heart. That tent was their home. Look at it (destroyed by law enforcement). This is why I say I don't have much, but what I do have I'm grateful for because that was me at one time. That was what I would be like. And I look at those people and relate and ask them how they're coping, how they're living." (AA, UK)

As described by participants in both Liverpool and New Haven, rough sleeping became a reality when all other opportunities for better living conditions were exhausted and connections with family and friends were broken. People in Liverpool and New Haven did not become homeless when the ran out of money, they became homeless when they ran out of human connections.

"You have people in New Haven who haven't been housed in 15 or 20 years. They don't know what to do. If you give them a corner, they know how to curl up and sleep in the corner, like as if they were animals. We had a guy who was sleeping on the road homeless for four years and he was sleeping in a bathtub. It took him almost a month to get out of the bathtub because he was used to that confined space. And on his little boat [in a dirt lot] that's all he had." (RL, USA)

As explained by those participants who have experienced periods of rough sleeping, people in this situation were unable to afford basic needs and were under extremely stressful conditions which effected judgement and increased the frequency of stigmatizing and discriminatory interactions within their communities. Additionally, rough sleepers were disproportionately in contact with law enforcement due to the very nature of rough sleeping. It was illegal in

New Haven and parts of Liverpool City Centre to sleep on sidewalks, in doorways or in parks. Sleeping rough in Liverpool City Centre violated the nearly 200-year-old Vagrancy Act with punishment of up to £1000, although fines were rarely, if ever imposed. In New Haven, SB 896 was passed in 2013 which provided those in New Haven considered homeless, firmly established civil rights as a protected class who may not be discriminated against in employment, housing or public accommodations. In both communities, the responsibility to enforce these ordinances fell to local police departments. Police, as the participants reported, did not have the authority or ability to provide temporary housing or shelter to rough sleepers. Police had the authority to remove rough sleepers for violations of law such as trespassing and were often met with resistance and resentment from rough sleepers who were void of other opportunities for shelter and were living under life threatening conditions.

As participants explained, these interactions between rough sleepers and law enforcement tended to reoccur until the homeless individuals left the area on their own or were arrested and taken to jail. Similar to a medical practitioner with patients who do not follow their dosage advice for prescription drug administration, law enforcement*'s* frustration with rough sleepers often led to harsh, unwarranted and unjustified punishment. Those PWUD and homeless individuals interviewed said they needed thoughtful, professional physical and mental health assistance. Participants in both Liverpool and New Haven described the experiences of eviction as stigmatizing*,* abusive and an example of institutionalized and systemic discrimination against people who were homeless and without a fixed address *(NFA)*. Participants in New Haven who were Black, experienced racism from law enforcement and experienced verbal threats of arrest, theft of illicit drugs and experienced damage and loss to personal property.

"I was living in hell at night, constantly being bothered by the cops, shouting nigger this and nigger that. I was pretty deep in it [speedballs] back then and I couldn't even look at my own reflection, like in the glass right here, in the windowpane. I was just so into me me me me me and that's all I wanted. I

wasn't going to waste my time on anything or anybody else but the drugs. But then I ended up getting picked up and incarcerated for seven years. It was the first time I'd ever been in a big prison. I accept what I was and what I did to get there. It wasn't easy on the streets for a black man. So I decided that that life wasn't for me. I was clean for so long. I had stopped from using drugs, hardcore drugs. They were like obsolete to me. I can't imagine what it's like now in prison. I'm not trying to kill myself anymore, but being a daredevil, I tried to drown myself a little bit." (MR, USA)

On forced eviction from a site, personal possessions were often uncollected by law enforcement which compounded personal losses and further harmed the individuals through the inability to maintain safe and secure housing and the inability to maintain ownership of meaningful and necessary possessions. Participants in New Haven verbalized how choosing to move away from downtown New Haven was socially isolating but provided benefits as the hard-to-reach area beside the East River is one of the only sites to keep a tent undestroyed by law enforcement actions for an extended period.
To further complicate the activities of daily life, participants in Liverpool and New Haven described how rough sleepers often have no steady income and are often persuaded or motivated to participate in illegal activities to earn cash or drugs, placing them at risk of (re)arrest and (re)imprisonment.

"When somebody is homeless, the only thing that they can turn to is drugs because that's how they are going to meet people and get into people's houses, you know, if they get involved in drugs." (RL, USA)

"Not having any money, you will always turn to drugs. You see, with drugs you don't need a title to go make $5. You don't need a suit and tie to go make $5. All you need is the willingness to take these drugs from point A to point B, and you make five or ten dollars. But when you ain't got nothing, $5 or $10 is a lot of money." (RL, USA)

As indicated by the participants in both cities, financial needs leave rough sleepers with few options for survival. Participants in Liverpool explained

begging was not an early-stage choice for earning income, because it is less lucrative compared to other activities. Three Liverpool participants described episodes of begging or panhandling, as the act is referred to in the US. Asking strangers for money was witnessed as a common activity in Liverpool City Centre, trending up in the evenings when the city's bars and restaurants bring visitors to the area and remained an essentially legal and socially acceptable activity in the City Centre area. Participants witnessed and described the activity in downtown New Haven, but no participants described the personal experience of begging or panhandling in New Haven, perhaps to shield themselves from discriminatory judgement or from the stigma associated with asking strangers for money. Anti-panhandling laws in Connecticut continue to exist, but since 2013, people who are homeless and unaggressive are allowed by law to ask people for money. Panhandling in New Haven is said to increase the likelihood of unwelcome interactions with law enforcement which are likely to end with some form of punishment..

Participants explained that without financial support or a job, the need to earn money will expand from theft, to include participation within the illicit drug trade, sex work, burglary or larger criminal activities, commonly including stealing cars. In both cities stealing cars was a popular option to earn money or large quantities of drugs. Without health-related interventions, participation in these activities almost always led to eventual re-arrest and re-imprisonment by law enforcement for criminal behaviors.

"That's how I feel. Drugs and alcoholism are intertwined with homelessness because that's where you end up. That's a fact. I don't know anybody that used (heroin) like me, that didn't end up in that place. Everybody I used with down in (a UK city), we all ended up on the streets and most of them are dead now. (PJ, UK)

The options available for local police in Liverpool and New Haven, who were responsible for maintaining safe communities and the enforcement of local laws pertaining to drug related crimes, were few when dealing with homeless individuals. Frequently, police departments, such as those in New Haven (and

to a significantly lesser extent Merseyside), had no healthy alternatives to the (re)arrest and (re)imprisonment of a rough sleeper for either drug crimes, public intoxication or trespassing. Participants reported that Merseyside does refer unaggressive rough sleepers to shelter beds when possible. The unfortunate result for rough sleepers in both communities was often a mix of arrest, confiscation of personal possessions (if not left uncollected on the street) and eviction from the problematic location. With law enforcement unable to provide significant options to arrest or eviction, the issue often led those arrested into the court system where judges were tasked with making decisions for the individuals about housing**,** homelessness and drug dependency concurrently.

"When I was living on the streets, I was selling drugs. I was selling pills and they charged me in July with possession of pills and possession of heroin with intent to sell. So I went right back to jail and stayed for 45 days and then my boyfriend came and took me out. And then I went back and did the same thing again. So I have felonies now." (LC, USA)

Participants in Liverpool and New Haven described experiences of stigmatization, discrimination and violence when interacting with law enforcement. One Liverpool participant submitted an image of the Bridewell jail in Liverpool, a place where the participant spent many nights due to both his heroin dependency and arrests for crimes committed in the pursuit of money to maintain his drug habit.

This Liverpool participant explained how in the 1980s and early 1990s, Bridewell was known for being a Victorian era jail, replete with iron rings in some jail cells where particularly troublesome individuals were handcuffed so they must stand for hours as punishment. He described being badly beaten by police while handcuffed to those iron rings on more than one occasion. He described how asking to see a doctor after receiving such a beating was met with a photograph of the doctor rather than an actual visit by a practitioner. He explained how over time, he and his mates learned to hide their heroin dependency in Bridewell due to the fear of being physically beaten and

discriminated against for their heroin use. He learned it was better to “rattle and sweat quietly”, as he described his symptoms of heroin withdrawal, rather than admit to the officers that he was a heroin user and suffer repeated physical and emotional abuse from law enforcement in his own city. According to Liverpool participants, the retired supervisor of Bridewell from this era, known for his unique handlebar mustache and history of physical abuse of inmates, continues to live in the greater Merseyside area.

“When you went to jail (in Liverpool) as an addict, you kept it quiet. It wasn't really something you went into prison and said you were using. […] So we go in and we get in there and we're all withdrawing now, because we've been in the police station all night, and we're all withdrawing and the doctor in the police station gave us a few dihydrocodeine and a sleeping tablet, but when we got to the prison, my friend was already in there and he had been remanded and he said don't tell them that you're using heroin. […] So they asked me if I was using [heroin] and I said, no no no. And they said, are you sure, because you don't look too good? And I felt like shit, but I wasn't going to say nothing. But my mate behind me, when he went in and they asked him the same thing he said, yes I am. So when you went through, you went and sat in the cage. So we're all sitting there and the next thing you know a big white rush of hospital staff members called his name out, and I said, what have you done? […] He started laughing like it was a big fucking joke. And they came and threw him in a padded cell for the week and they pissed on him and they kicked him for the whole week. And that was when I learned never to tell. And I remember being on my last prison sentence when everybody was on methadone scripts in jail and I was telling kids about that story and they weren't believing me. That's how you got treated for being a heroin addict back then. You didn't tell them. What I learned the first time I went to prison was how much you missed heroin. I just wanted to get the hell out and use again.” (PJ, UK)

Liverpool and New Haven participants also described several examples of stigmatizing and discriminatory experiences at the hands of law enforcement. Physical violence by police, destruction of personal property and being

detained and driven to other cities and released in gang-controlled neighborhoods were experiences described by New Haven participants. The most common experience discussed by Liverpool participants was being arrested and imprisoned for petty crimes related to opioid dependency and forced to remain in jail for a period of that allowed for detoxification before release.

"You know there can be many different contributing factors for people who are homeless, but I'll bet you that the people who are homeless that have heroin addiction problems have a lot of similarities. You know they don't just arrive at being homeless overnight. They slowly go through losing the things that connected them to humanity. And when you run out of them, you're left with nothing. In my own case I owned my own house and I had a mortgage and you know, I had five figures in the bank and I was comfortable. And yet, you know when my addiction took hold, I ended up in a place where I was sleeping in the park because I sold the house to take drugs. And the wife left me. And then the family got sick of me taking stuff from their houses. And then friends quickly got sick of me doing the same. And it was when I got toward the end of the line, it all happened really quickly, the last few weeks before I went homeless. I think that's what happens with a number of people, they go down the ladder until the end up being homeless." (CB, UK)

In New Haven, according to some participants, imprisonment at the New Haven Correctional Center was used as an institutionalized form of forced detoxification for many years past 2013, when a pilot project implemented OST and group therapy for a selected, few inmates, but not all individuals with opioid dependency problems. The Connecticut Department of Corrections (DOC) had plans to expand the use of this treatment modality beyond the 3 facilities currently providing OST, but a diagnosis of OUD is required for inclusion in this expanding program and wait times for medical assessments for OUD continued to be the greatest impediment to the introduction of opioid treatment services for inmates in 2021.

The interactions between people of color and law enforcement in New Haven were described as a historical consequence of long-standing racial and socioeconomic disparities which showed a quantifiable and disproportionate rate of interactions between Black community members and police. New Haven population statistics suggested that approximately 54% of residents were people of color and that Blacks, Latinos and other people of color have disproportionately faced arrests for drug possession and drug dealing offenses relative to their representation in the population. Economic disadvantage and racial discrimination have traditionally been the main drivers of disparate drug arrest patterns in CT as well as throughout the US. Economic disadvantage has created these disparities as limited community resources and poor job prospects have necessitated and encouraged the sale and use of illicit drugs in the most deprived communities, which included cities like New Haven and Liverpool. Being a Black or Latino opioid dependent individual in New Haven was reported to increase your chances of police interactions and arrest, which served as potential evidence of how institutionalized racism among law enforcement and the stigmatization of opioid dependent individuals continues to occur in most US cities. In CT, Black people constitute approximately 11% of the state population, yet make up 44% of those in prison (CT DOC, 2021). Issues of racism were not confined to New Haven as participants explained how economic disadvantage and racial discrimination were weaponized by law enforcement in Liverpool.

"It was having to do with the way the police "policed" people in Liverpool 8. I live there. And I know if you lived in that area you were scum. They used to freely use the word Nigger. And if you were a white woman there, well you must be married to a Nigger. So you're all scum. People were treated really badly." (LV, UK)

A female participant of color from New Haven explained her lack of housing assistance in Hartford, CT.

"When I used to be in Hartford, there is this corner where I used to sell, and the name of the little park where we used to sell was called Bum

Park. [It was] Bum Park because the drug addicts all used to be there. And we used to sell everything there. We sold dope. We sold crack. We sold marijuana. And we sold every kind of pills. Everything. […] I'm telling you, honest. It was hard for me. And I got clean living on the streets [of Hartford]. I was taking showers every day and I was convincing my friends to let me keep clothes there, and every day I had to pay $10 to take a shower and then $10 to put my clothes there and everything. So, for a year-and-a-half I was living on the streets. I don't recommend that to nobody. Because you suffer. You suffer a lot. And I see people now, when I'm clean, I see people living in the park, and that's no life."

Participants in New Haven and Liverpool told stories of law enforcement and how the sale of drugs was tolerated in some sections of each city, but not in others. In Liverpool, the Toxteth neighborhood was reportedly a more ethnically diverse and more socioeconomically deprived community where heroin was more commonly available and participants described police during the 1980s and early 1990s as more tolerant of drug dealing in that neighborhood than in other parts of Liverpool.

"It's funny, when I got into heroin, I lived in a really nice area, but I chose to spend all my time in Wavertree, Toxteth and Dingle. Those were the areas that I knocked about in. And at that point, even though the pubs were supposed to shut every day at three am, where my dad drank and where I went to go drink on Hill Road, all the pubs just stayed open and the police just let them do it. Similarly, the police used to let them sell drugs in certain areas of Toxteth, especially on Gatsby Street, they just let them sell drugs." (CB, UK)

"Marsh Lane had the highest injection reputation. And Queens Road. I've got pictures, you've got to see these pictures. We worked, we went down James Road which is just over a few blocks, and it was full of derelict housing at the time for a few blocks. And we collected all the dirty works and I've got pictures of that." (AM, UK)

In New Haven, participants described the historic difficulties of finding heroin and cocaine in the downtown area, but a ten-minute walk to the Dixwell neighborhood, with its densely populated, government-subsidized housing tracts, or a 5-minute walk to The Hill neighborhood, provided ample opportunities to find illicit drugs for sale, including heroin and other opioids.

“In my neighborhood they only sell K2 and weed. And that's good because I don't know who sells the other stuff. Like people say if you need dope you have to go to the projects. I know they have a lot of projects in New Haven, but I don't go the projects.” (RAL, USA)

“Once they [homeless people] get involved with drugs, whatever you have is what they're going to use. If they have K2 [spice] then you're going to use K2. If you have oxy [oxycodone] then they're going to do oxy. If you have alcohol then they're going to drink, because they don't have the money. So, whatever you give them, that's what they're going to use.” (RL, USA)

5.4 Theme Two

Cyclical Arrest and Imprisonment are Obstacles to Health; Prison Contributes to Opioid Use

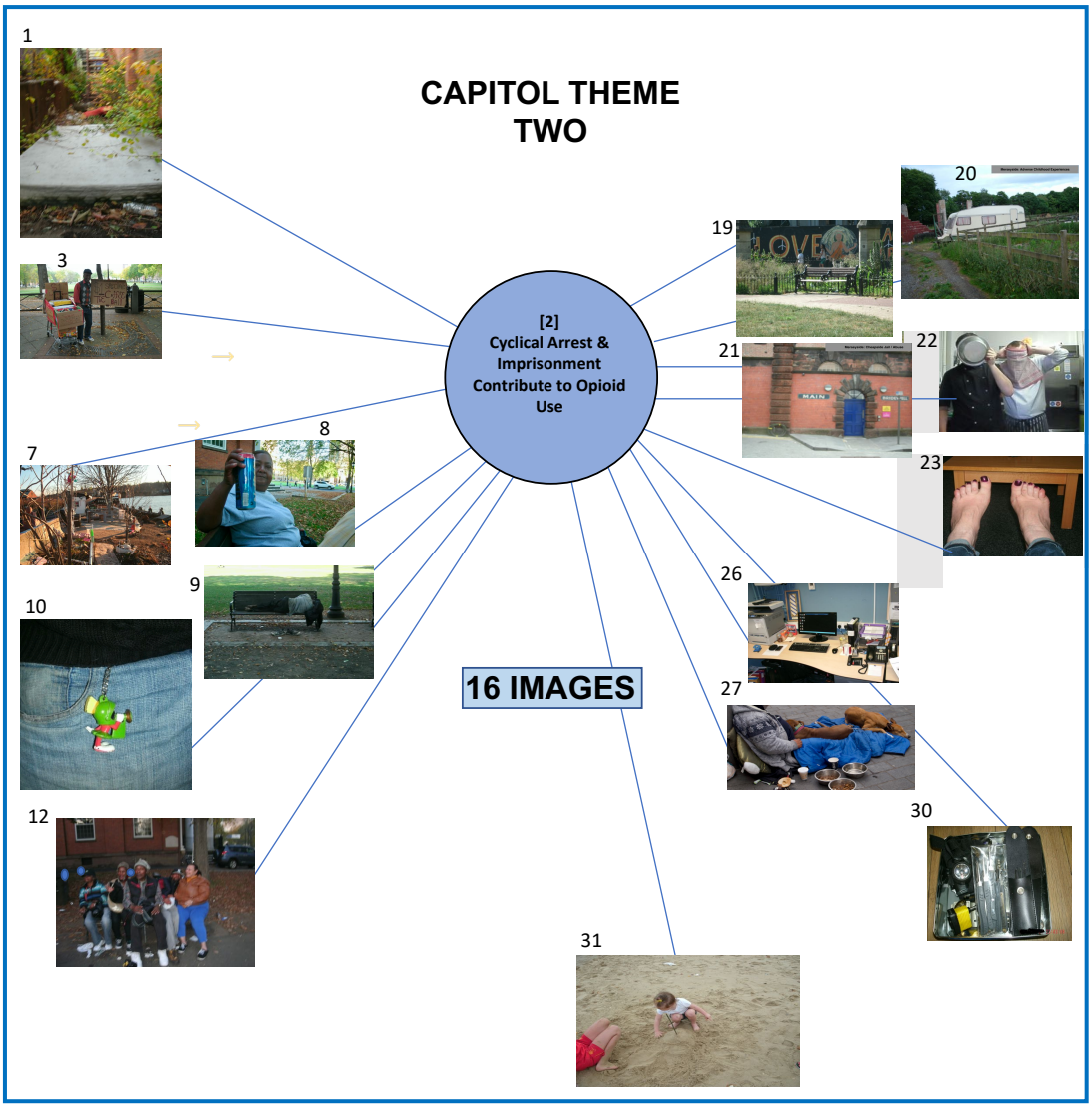


Figure 5. Capitol Theme Two and Associated Capitol Works

Jails and prisons were described and experienced as a form of abstinence-based drug treatment, as a repository for stigmatized and marginalized people punished for drug use and as a form of temporary housing for people better

served by mental health care and hospitalization. Re-arrest and cyclical imprisonment were stigmatizing and had a lasting stigmatizing impact on an individual's ability to participate in the community, enter the job market, participate with family, acquire housing and qualify for financial assistance.

"I stopped [opioids] by going in and out of jail, I guess. It was jail. I dried out in prison. It was rough. Especially back then. They didn't give you nothing. In the early 90's, just cold turkey. After a couple of months, it was alright. I stayed clean basically through the whole bid. A couple of times, I used dope inside. It was easy to use inside back then. If you wanted it, it was pretty easy. I was locked up in Enfield at Carl Robertson Correctional [in CT] for a long time." (RW, US)

Unlike in Liverpool where universal healthcare is provided to an individual registered with the NHS, both inside and outside of prison as a human right, those participants arrested and placed in the New Haven Correctional Center or any other CT correctional facility until recently, were not provided with mental health services as healthcare is not a human right in the USA. Further, under federal law, prison health care was the responsibility of the institution, rather than the responsibility of state and federal Medicaid and Medicare programs. Of the fourteen state correctional facilities operated by the CT DOC, only seven facilities offer treatment for approved and previously diagnosed opioid dependent individuals in 2021. Beginning with a pilot program at the New Haven Correctional Facility in 2013, Medication for Opioid Use Disorder (MOUD) was provided for individuals with a prior diagnosis of OUD before entering prison. The recent plan for expansion of MOUD in CT prisons included a cognitive-behavioral treatment curriculum developed at Hazelden, which served to address both criminal and addictive thinking to benefit imprisoned individuals with drug dependency problems and treated 425 patients in 2020 (CT DOC, 2021). Across the US, MOUD continued to be widely unavailable at over 80% of jails and prisons nationwide. A 2019 report by the National Academies of Sciences suggested only 5% of people with OUD in jail and prison settings in the USA receive OST (NASEM, 2019). Formal evaluation in the prison setting for a new diagnosis of OUD in

Connecticut jails and prisons continued to be rare, a rate similar to most state prisons throughout the US. No New Haven participants had the experience of receiving MOUD or OST while imprisoned in CT, with or without a diagnosis of OUD.

"We need to give them (women released from jail) Super Groups. Support groups. I go to the women's support groups a lot. They help me. I don't think I could be successful without support groups. I have to go more than one year clean. Because you know you can relapse. I need a year or more. Because I know my best friend he relapsed after 20 years clean. When his wife died. That was emotional because me and her we were like sisters. That's why I say for now I have to keep clean. One day at a time. I have five grandchildren- 3 girls and 2 boys. I went to Hartford on Friday, my first time by myself going to visit my family. And I'm proud of myself because I saw people selling dope, and I didn't get crazy. Yeah, I'm proud of myself. I thought this time I wasn't going to make it." (LC, USA)

Participants wanted services and treatments for opioid dependency in jails and prisons and understood the benefits of detoxification and MOUD prior to release from jail and prison. Changes to increase MOUD would require state and federal policy modifications by representatives, which are politically difficult to justify as budget cuts get prioritized over increased spending on stigmatized and marginalized people with opioid dependency in prison.

"…it's the drugs and the drug problem out here; it's just terrible and a lot of people don't get to see that it cuts across all races, all ages and just doesn't matter. When you become addicted, your life is just different. You're dealing with danger in real life and I'm sure a lot of these youngsters probably don't make it, not even the drug dealers. These people get shot and go to prison. They don't have a whole lot of help in prison. As a veteran, I can still interact with the VA, I can go to groups, I get to see doctors, (for us) our doctors are there to help get you healthy and they do. I don't know if they (non-veterans) have things like that in New Haven. Once you come out of jail, you're on your own as far as groups or trying to find housing […] it's just tough." (BW, US)

On release from jail and without addressing the underlying issues that affect both opioid dependency and broad homelessness, individuals often returned to their communities, most frequently using the address of a relative who agreed to participate in the safe life transition from prison to being home on parole. Having a home to return to after release was reported by the participants as a large hurdle. Participants emphasized if you use the address of a family member, you are not and will not qualify for benefits as a homeless individual. Participants explained that on release from jail, they often had a strong desire to re-enter their social networks, regain their places in their social hierarchies and restart their search for safe housing and financial stability, all of which brought challenges and stress to their newly released-from-prison status. As evidenced in Chapter 2, opioid dependent individuals recently released from prison were at extremely high risk for opioid overdose in the first 14 days of release (Binswanger, et al., 2007). For scale, approximately 25%-65% of individuals in US jails and prisons meet the diagnostic qualifications for OUD (Fazel, Bains & Doll, 2006; Chamberlain, et al., 2019). Without an effective evidence-based treatment strategy and follow-up care, approximately 95% percent of individuals with problematic opioid use disorders released from prison, return to the use of opioids within 6 months (Chamberlain, et al., 2019).

“Most people who go on methadone maintenance scripts in jail never seem to come off. They are on it for the likes of eternity. I think a lot more time, effort and energy should be spent on trying to support the addict with the option of becoming clean and abstinent, rather than on a methadone script. Because you’re still using [heroin].” (CB, UK)

“It's just like they say after jail, we'll sort it all out for you. Don't worry. And then that's it. Three months later, or by the time six months goes by, I got tired of waiting. I had always gone back out and taken my drugs again.” (AA,UK)

“I didn’t know that I had to change more than just stop using. I was in detox more than 20 times. I can’t tell you how many times I have

withdrawn from heroin in jail and went into treatment. When you don't have any money and you don't have any family and you might not have a job, well, there's dozens of barriers, but for me the biggest one was myself." (CB, UK)

"What I do find is that people quickly lose the impetus to change when it is not followed up, straight away. Very few people who are dependent on heroin, or any drug, don't usually have a long-term plan. It's linking together the people who, at that moment say, I want to start recovery. I feel like the place where so many of them are lost, is coming out of prison. So many people come out of prison and they've gotten clean in prison. I know not everybody gets clean in prison, but a good number do, or decide when they're leaving, I don't want to be coming back here. And the main reason that they are in prison is because they have been alcohol or drug dependent and were either selling drugs or doing things on drugs or getting money to buy drugs." (CB, UK)

This repeating cycle of opioid dependency, interaction with law enforcement and re-imprisonment was common for many people with long-term opioid dependency in the study. Some participants in Liverpool explained that they had been through this cycle over ten times, with one Liverpool participant saying he had participated in prison-based opioid treatments over twenty times and always returned to his mates and the use of smokable and injectable heroin until he turned age 44.

"For over 20 years people tried to help me and I quit and restarted throughout those 20 years over and over and over again in prison. And there were people in centers and service providers who spent decades trying to help me. And it wasn't until I got to about 23 or 24 years of that before I decided that I was going to change myself and I'm very thankful that those people tried for 20 years to help me because I needed that and so I'm here to tell you that you have to try everything and you have to have everything in your bag of tricks and you also have to have an undying amount of energy because for somebody like me I didn't learn the lesson the first 35 times they

came to me, but you know after a hundred times in 20 years, suddenly I got the message." (CB, UK)

Ten Liverpool participants described their experiences with harm-reduction and specifically their transitions from heroin user in prison (for repeated crimes such as drug dealing, shoplifting, larceny, drug possession and burglary), to released inmate with a script for daily methadone or other opioids. These participants said having access to prescription opioids reduced the need to participate in the local drug economy, however several said they continued to participate in criminal activity or sex work and used the prescription opioids to quell withdrawal symptoms while continuing to use additional drugs, including heroin. Most described episodes of reentering jail while having a methadone script, an indication that prescribed opioids alone, were ineffective at improving the overall health of the drug dependent individuals, ineffective to keep them from reentering jail or prison and ineffective at reducing their overall participation in drug-related crime.

"When you get out (jail), you've got to stick to the methadone and I knew loads of people who used to do the methadone and be fine, but on a Friday night when they got that money, they'd go out and score. It was like buying a cream cake on payday." (SW, UK)

"Because this is the way that the judge, (thinks) prostitutes must learn that these are the hazards of their job. I went in front of that same judge 6 weeks later for 3 shoplifting charges and got 18 months in prison. […] And that was my struggle, to try and prove to people that I was worth something. So, it took me awhile to get myself together after that. After that, I really went bad on the drugs. The crack. I even started injecting heroin again. I really went to a really bad place. I just didn't feel I was worth anything. […] So that was a really fucking hard thing. My mom gave me a reason to escape. I couldn't do it anymore and I didn't see my family again until I was 31. And that was when I tried to kill myself. I tried to kill myself and that's when they realized I needed help, but I still never got it. And now I'm 51 and then I was 27. When

it (rape and kidnapping) happened, it was 24 years ago and I've still never had real counseling to this day. I tried to just cope with all that." (AA, UK)

Participants from Liverpool verbalized an understanding that although methadone scripts were widely used as a form of treatment for opioid dependency, there were few or no treatments offered to modify the behaviors surrounding heroin and methadone use. Over time and after multiple episodes of relapse to opioid dependency, many participants found participation in peer-supported groups to be an effective treatment for opioid dependency as they aged and as support groups gained cultural acceptance among PWUD in Liverpool. Participants credited peer-supported recovery treatment with the potential to encourage a steady, incremental transformation, through knowing there were others in the community who maintained long-term sobriety.

"When heroin first come to Liverpool, I was using heroin for 12 months before I even realized what it was. And that was the same for a lot of people that I know. And I don't believe the government […] knew what was going to happen […]. I say to people, man, you can't blame the government for the drug addiction because they didn't know where it was going to come from. Nobody knew when things first started and we were all smoking heroin, we didn't know we were going to spend most of our fucking lives in that, in and out of prison and in bad places. We didn't even dream of that." (JL, UK)

Peer-to-peer therapy and counselor-led support groups for alcohol and drugs were effectively used and widely supported by the veterans at the West Haven VA facility and all Liverpool participants. Four veteran participants in the New Haven cohort detailed the ways in which the support groups at the VA campus were central to their individual recoveries. Participants in New Haven without access to VA services visited other well received support groups in the area, including a women-only support group with an excellent reputation for inclusion and mental health and housing resources.

"Well, things that help me not get high are being around this group of people here at the VA. Working (volunteering) here keeps me busy. I get to see the

world as it is, and I get to see people when they're in a stupor, when they're high. And there by the grace of God, there go I. Because that person could be me, you know? It keeps me in touch with reality- to do the right thing. And I gotta do the right thing not for anybody else but for me. I gotta do this for me and as long as I'm doing it for me then everybody around me gains." (BG, USA)

Participants in Liverpool were divided about the care they received from the NHS and the care they received from third sector drug treatment institutions that existed outside the NHS system. Participants explained that providers were constrained from expanding individualized mental health services to clients due to increasingly frequent austerity measures, budgetary requirements and NHS obstacles to approving mental health referrals.

"I don't believe that every junkie has not cried their eyes out every night, no matter who they are. I know they have. No one wants that life, do they? You might at the start, have thought that it was a bit of fun but once your trapped nobody wants that. Absolutely not I don't think, it's just hard to get out of it isn't it? And you know what I realized? If you're 40 and you suddenly get off it, you've got nothing. Don't forget all your council mates, all your counterparts the same age, who haven't been using drugs they have a few quid and you've got nothing, so you're going to end up back in jail again aren't you? I mean you've got fucking nothing. So, you're going to end up back in jail again, aren't you? You're going to go what the fuck? It's very hard for somebody who's 40 or 50 to get off of it. And to stay off, you've got to have something." (JL, UK)

5.5 Theme Three

Relationships Affect Opioid Dependency in Profound Ways; Human Connection is Everything. The Active Role of Grandparenting Can Positively Affect Opioid Related Health.

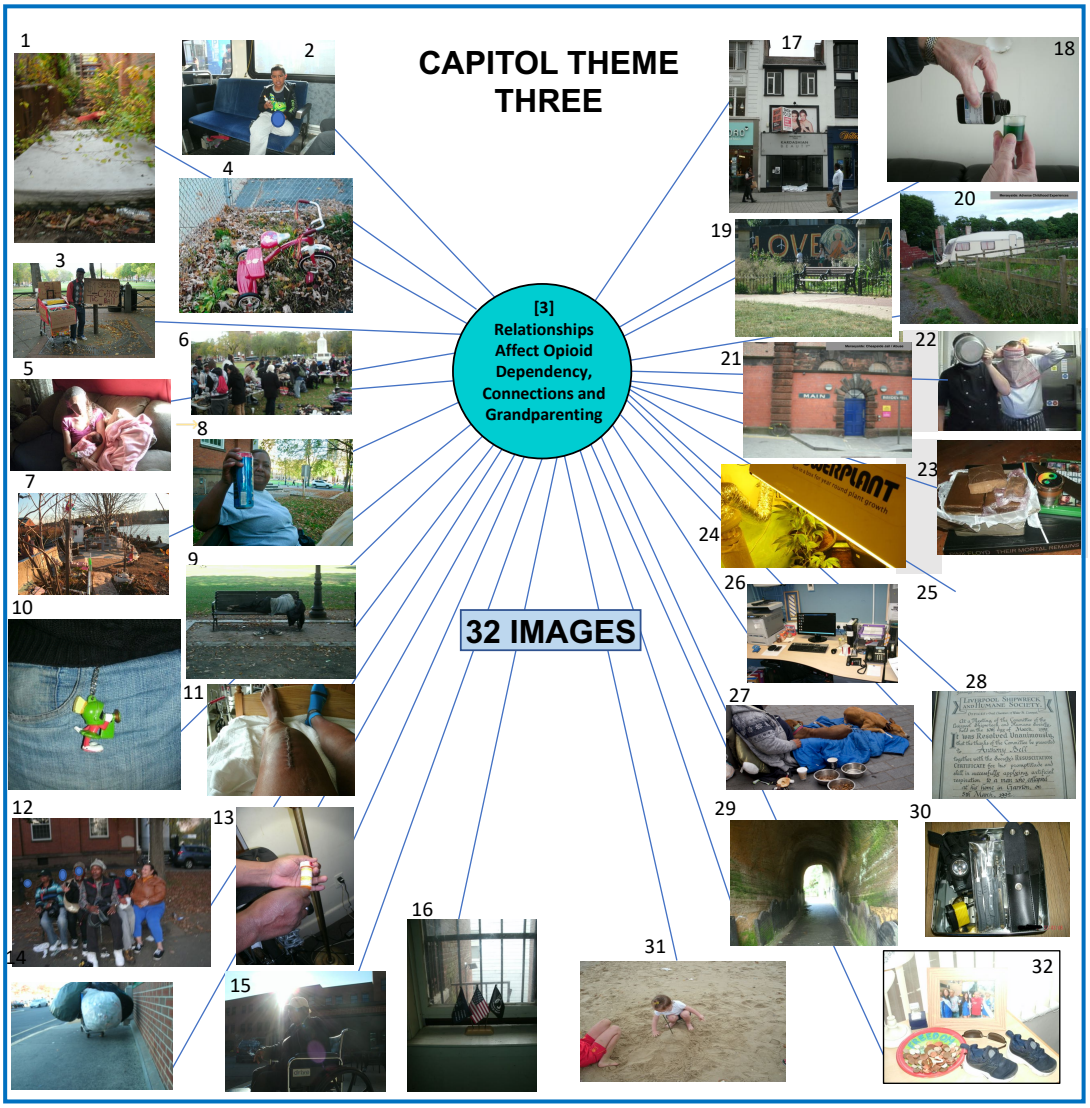


Figure 5. Capitol Theme Three and Associated Capitol Works

Relationships both positive and negative, significantly affected opioid use in complex ways and shared a significant overlap with adverse childhood experiences (ACE) and adult traumas, which appear within *Capitol Theme Four.* Personal connection to grandchildren was strongly associated with healthy living and as a motivating factor for achieving recovery goals among participants in Liverpool and New Haven. Engagement with family through the role of grandparenting was found to foster re-connection in broken family relationships, increase opportunities to earn trust through responsible behaviors and actions, improve self-esteem and self-confidence and counter depression by eliciting happiness. Some participants who experienced social isolation and hopelessness also described estrangement from family, friends, grandchildren and work due to lost trust through lying, deception and secrecy related to opioid use, suggesting that meaningful interpersonal connections to others, including family members is beneficial to health.

"A lot of times you have people that have family, but they want to do the drugs. And they have kids and they still want to do the drugs. They don't want to come out of it. And that's who falls through the system." (RL, USA)

The overlap between *Capitol Themes 3 & 4* regarding personal relationships and the experiences of childhood and adult traumas was evident in the narratives from the participants. Some participants were more comfortable discussing these issues and were able to articulate the nuances between these experiences. A participant who grew up in Liverpool's Toxteth neighborhood for most of their life, provided insight on how and why they became opioid dependent.

"I went there and I thought I was going to get counseling and everything, and every day you get less. It was a big fuss to see him [the doctor] and when I got there, they were giving me 50 milligrams of methadone a day for the rest of my life. You're on a methadone maintenance [script] for life. When we got outside, my mum said, "They just wrote you off." At [age] 19 they have just said to me well, what has caused you to do this?

What are you scared of reality for? Are you just escaping reality? And I said well, I was abused as a child sexually, maybe I needed a little bit of support. I didn't put more on my family as they were already broken. I had broke my family and I had to live with that at 19." (AA, UK)

As described in Chapter One, the heroin epidemic in Liverpool as well as in other parts of the UK, was arguably the result of a combination of 3 factors: an economic downturn which negatively affected jobs for workers, especially for 18–25-year-olds, increases in the population densities of deprived urban areas of Merseyside and a widespread influx of heroin by organized crime into lower socioeconomic communities for financial profit (Parker, et al., 1998).

"Liverpool was just in a position where we had a very organized criminal underground. You had crime families who would buy and become a distributor for heroin. Liverpool was a distribution hub for heroin to Scotland, Edenborough, Glasgow, Dublin, Belfast, basically, most of the northwest. Most of the north of England and Scotland had it and it came through Liverpool and got shipped out. And some of it dropped out here and some of the young kids got a hold of it and found that it gave them a reason to get up in the morning." (SW, UK)

These unique circumstances were shared by many in the Liverpool cohort. In New Haven, the introduction of participants to opioids was similar, but more culturally endemic to the 3 largest and most socioeconomically disadvantaged cities in CT, which were, and continue to be Hartford, New Haven and Bridgeport.

"I had to be like 23 (years old) and went to visit my cousin in Hartford for his birthday, he had cocaine and everything. He put some dope (heroin) in with some cocaine. I already knew what a speedball and shit was, so that wasn't no problem. But this particular incident, this is what kind of started it. Because after I sniffed that shit, I never felt as golden, yo, as I did. I had never felt that way before in my life. Do you know what I mean? So that was the beginning of the demise, or the destruction, or whatever, but that's how

that got started for real. I really felt it. It was the turning point when I started buying that shit. Just years and years at that shit. And today you still want that golden feeling." (OS, USA)

Relationships were described as both a cause of opioid dependency and a reason to stop using opioids by the participants in Liverpool and New Haven. Relationships were described as a major factor in how and why an individual was inclined, motivated, or persuaded to initiate opioid use. Among all participants, drug and alcohol use was introduced by either family members, friends or intimate partners as a recreational activity for enjoyment.

"I loved the fact that my dad went out to the pub every day and went drinking, because from the time I was a young teenager, I would go with him and I would meet his mates and he would get me beer. So, I loved that life. He was a dock worker and he loaded boxes his whole life along with 30,000 other fellas [on the Liverpool docks]. And I loved that life because I loved to go to the pub and spend time. But after a while, it didn't seem like that was enough. I wanted something more and heroin definitely gave me that." (CB, UK)

Participants from Liverpool were typically introduced to smokable heroin between the ages of 15 and 25, by siblings and friends, whereas participants from New Haven were introduced mostly in their twenties by the same social groups and also by medical practitioners for the alleviation of chronic pain symptoms.

"In the early 80s there was an absolute massive, massive flood of heroin in Liverpool and the people I used to work with when I first came to Wirral were all in their mid-20s and had all been at heroin for at least 10 years and got into it literally at the school gates. And I used go to a club, by the bull ring, The Bronte, and one day there was a girl she was about 15 and she was saying have you tried that heroin stuff? She said, you can't get addicted unless you inject it. So totally ignorant about it. And I firmly believe it was allowed to happen. If you check out the areas of really

problematic heroin use, they're all areas of high unemployment, massive deprivation, poor education, and all the rest of it." (LV, UK)

"My knee had problems so the doctors at the VA started giving me opioid pain medicine. They had been giving it to me for about thirteen years and then something happened, and the President decided that the hospitals were giving out too many opioid medicines, so the VA started cutting back and making people sign (medication) contracts. One mistake and you were off, so I made a mistake and they cut me off. That didn't stop my pain, but they didn't care at the time." (RW, USA)

Interpersonal relationships were the basis for interactions within family systems and most commonly served as the innermost network of an individual's ecological environment. Family relationships may vary in framework, but the value of family and intimate partner connections endure. As children mature, lived experiences influence which relationships grow deeper, which relationships remain the same and which relationships deteriorate or end. The unique experiences of each individual and the circumstances with which lived experiences occur can influence the degree to which each relationship changes.

"I had a great childhood. I loved growing up my family was great my mom and dad were fantastic and all that kind of stuff, and it was all a great adventure. It was fantastic and I loved it. I had that stability, and I still did drugs." (SW, UK)

"If you ask me who my significant other was when I was a child it was my grandmother. She's the one that I think of as the person who loved me. My mother was a witch. No, she wasn't a witch, God love her, she had a terrible time with my dad." (LV, UK)

"I never knew my mother, but […] when I was seven years old, somebody kidnapped me from my grandmother in Puerto Rico, who used to take care of me and wait for me every single day from school. And somebody kidnapped me when I was seven and molested me and

everything. And my grandmother had to pay a ransom. So, everything was tough for a few years, then when I was 10 and a half or 11 my period came for the first time and I told my grandmother. Soon after, my grandfather, when he got drunk, he raped me, and I was 11 and a half. And after that, I came to live with my aunt in the USA." (LC, USA)

Interpersonal relationships extended well beyond the family unit and ranged from incidental personal relationships to intimate partner relationships, each providing strengths and weakness that contributed to the level of attachment a person felt for another. As relationships changed due to life experiences, participants often had a hard time describing how they felt about others within their ecological systems as relationships were complicated and dynamic.

"My wife had left, we had mortgaged my house on a [heroin] binge, and I spent £ 70,000 in 6 weeks. Then I dropped my mother's house. I had stayed in friends' houses and was taking things from them […]. I found myself homeless and I was sleeping in the park and I had my hand out for money. And I hated everybody in the world. And then one night, when I was withdrawing, I was terrified and I decided I was going to kill myself. (CB, UK)

Participants often had difficulty in describing exactly how they felt about others and preferred to explain the experiences between themselves and others as a way of detailing the complex nature of each individual relationship. A woman from Liverpool described the way sex workers looked out for each other and protected one another.

"Out of prison, I wasn't a very good robber. I was in a hostel and girls were going out and doing it [sex work]. So slowly but surely you go, and the first time it was like just to watch the girls' backs and we used to take the registration numbers off the cars that they got into, but that's all gone to the wayside now, it's not like that anymore." (AA, UK)

In refraining from describing a family as traditionally nuclear, binuclear or postmodern, this paper defines family more generally as a *"latent mix of kin*

connections" and a framework of *"continually shifting linkages that provide the potential for activating and intensifying close kin relationships."* (Riley & Riley, p.169, 1993). Important aspects of core family relationships include multigenerational influences on children and the role grandparents and extended family members play in socializing and supporting children, particularly after a family experiences divorce, death of a parent or child, imprisonment of a parent or child and institutionalization of a parent or child.

"I do know quite a few people who have a big issue with their fathers and their father's relationship with their own grandchildren, because well, he wasn't like that with me. And it's proper jealousy. And I think something happens as you get older that you have this connection with little kids who'll look at you a different way and smile at you and I don't understand it. But I think if you take the drug use out of it, this can happen between older people and very young." (LV, UK)

"My granddaughter was born, but I was using heroin and I was in the depths of despair. It was such a dark place for me. I had lost everything. I had never known anything more than hand-to-mouth, I lived on benefits and I was spending all my benefits on heroin. I was prostituting myself for money and I was living like an animal in squalor. And she was born, and I was trying to be normal, you know. And my daughter had left my life because I wasn't really a mother to her and stuff like that. But then my daughter wanted to go to college to become a nurse. And she had nobody to look after her daughter. She asked me, "Mum, will you look after your granddaughter for two hours on Mondays and Wednesdays?" And I said yes. And this little child would be brought to my house and I was still on drugs, but I wouldn't do them while she was there. And I tried my hardest to be normal. So, I tried desperately to stop using and it was only through loving this child that I cried out one night for help to stop." (CE, UK)

Participants described the experiences of longstanding broken relationships resulting from drug use crimes which were easy to separate from, but also described relationships that they wanted to repair and return to because memories of the relationships were both positive and deeply meaningful. Most often, the relationships participants wanted to repair were with kin connections that were built on years and decades of trust before being broken. Often, when the participants spoke about the relationships they believed were worth repairing, they discussed their own parents, siblings and adult aged children. According to the participants, these relationships seemed the most impactful, meaningful and important to regain as they represented intimate relationships built over time.

"When I saw my family this weekend they said, oh my God you're starting to get fat again. That's because every time I get clean, I get fat. And I said please don't even say that I'm fat because then I'm going to want to start losing weight (laughing). But they're proud of me because I'm getting healthy. My family is everything to me. My two children, and my grandchildren were my life. My children give me the strength that I need. Even though my son left to Florida, and that was killing me, he calls me every day. We stay in touch, and he's proud of my getting clean again." (LC, USA)

Family dysfunction, including but not limited to the personal experiences and family-related experiences of poverty, violence, discrimination, broad homelessness, insecurity, sexual, physical and emotional abuse and systemic maltreatment were topics discussed by the participants from Liverpool and New Haven, but often without particular details. Family disfunction was a traumatic and difficult topic to discuss in detail and many participants were unwilling to provide examples of how and why family relationships were broken but described the detrimental effects of broken family connections and how their own parents as well as themselves, were neglectful, unavailable and/or abusive. Many participants described parental alcoholism and drug use, being raised by single-parents or multigenerational kin and the broad experiences of abuse by parents and guardians. Most often these subjects were mentioned

in the context of other issues and were not explained in detail to the researcher.

“For me it wasn't a thing about doing drugs and forgetting how horrible she was. It wasn't. It was like I was trying to sort it out. It was my problem. I think we’re all damaged to an extent and some people are broken. Some people are just broken. Some people can't or don't have whatever it is to try to fix themselves or to think that they can fix themselves. Self-esteem is gone. Self-worth is gone. So they can't think logically if you like. Say, do you know that poem by Philip Larkin, he is quite a famous poet?” (LV, UK)

“That's my grandchild, I was playing with him this morning because I don't get to see much of him now. His mum has just come out of rehab. His mum is a cocaine addict. She is an addict. And she has realized that she has a problem and her relationship is on the rocks. She has three kids and all that. Kids don't keep you clean as I know. As I know, kids will not keep you clean.” (JO, UK)

“I have grandchildren and they are a huge part of driving me forward to make amends to my daughter for her life. But through that, the love that I have for them is limitless. It has no bounds. I adore them, but there are many layers to it. There are many layers because I'm doing it for my daughter, as well. It's just a different love and being clean- my grandchildren have never even seen me smoke heroin. They have never seen me take a drink or a drug or anything like that. I am just their Nan. They see me as some sort of hippie. I just adore them. I think when they were small, I still had low self-worth and low self-esteem and then on the other side of the family [in-laws], they weren't like me. I don't even have Wi-Fi. Why did the grandkids prefer to be with me? I think it was because of the attention I gave them and the love. I had never felt like that until my grandchildren were born. I had never felt like that as a mother. It’s powerful stuff, isn't it?” (CE, UK)

Participants also described examples of positive relationships with others at times when they preferred to use drugs and remain isolated from family. These caring connections helped to change their personal opinions about drug dependency and helped to activate positive changes to their health and decrease drug use which served to benefit other fractured relationship connections.

As 24 of 25 participants shared the experience of being a parent, the relationships that connected them to their adult children were topics of conversation with the researcher, who also had children. Grandchildren and the role of grandparenting was a nearly universal topic among the participants in both Liverpool and New Haven. A majority of participants had positive reasons to discuss their relationships with grandchildren and were able to associate their roles as grandparents with mending broken relationships with their adult children.

"You love your kids, but your grandkids, they keep me on the right track. If I didn't have grandkids, I think I'd be doing a lot of drugs, and my grandkids, they help me with that." (LB, US)

"My grandson is the bright spot in my day […]. He is my center. He is the center of why all these other pieces come together […]. In one of the pictures, you can see that I am on the football field and sitting there freezing, to support him. He is really the center that makes the rest of this possible. He is so important because we get a chance to get it right the second time around. We can have all of the spoiling, but none of the consequences. I have a 12-year-old granddaughter who is in foster care, she has a brain injury and is autistic. But I get to see her. I haven't been able to see her lately because I have been sick a lot and she is easily compromised. But I'm looking forward to seeing her this month. I would like to see them remember the things that my grandmother meant for me, baking, cooking together and a spiritual lifestyle. All the things that I hope that he will remember (about) me when I'm no longer here. (DR, USA)

"Grandparenting gives you another chance to fix the whatever mistakes you could have made with your own kids. […] Through their whole lives they used drugs and they were never around their kids. That's why they call it the past because you can't bring the past back, but you could for the future. So, what you didn't do with your kids you could try to be a better role model for your grandkids. And what's better than teaching them what the street is about, because you were on the street. […] I told my kids what cocaine looks like and I showed them what weed looks like and what pills look like. If you go to a party and you lose sight of your soda, please leave your soda. Buy another one. Buying a new soda is not going to kill you but maybe if you drink one that will. […] But your grandkids are something that you do different. You try to fix whatever it was you couldn't do with your own kids. (RL, US)

New relationships were also discussed by the participants, brought about by positive health changes in drug use behaviors, positive changes in self-perception and self-confidence and through the experiences of meeting people with similar goals for sobriety. Group therapy, super groups and AA meetings were often the topic of discussion with the researcher and were most often positive. Group therapy was reported to be a highly beneficial experience for participants who found the need to establish new connections with new people. A few counselors and therapists were discussed by name for their dedication and help to curtail drug and alcohol use through methods of motivation and peer support since the 1980s and early 1990s.

"And now you see this guy, his case worker did a wonderful job with him, and [the case worker] would go on the first of every month to show him how to manage his money and help him get a money order to pay his rent. They got different donations for him with furniture, and his [new] place is spotless. The guy looks like a whole different person. He's shaved, he takes baths and he's a whole different person. But you see, it's because somebody took time with this person. You have to take a little time." (RL, USA)

5.6 Theme Four

Adverse Childhood Experiences and Adult Traumas Contribute in Complex Ways to Opioid Use, Broad Homelessness and Imprisonment

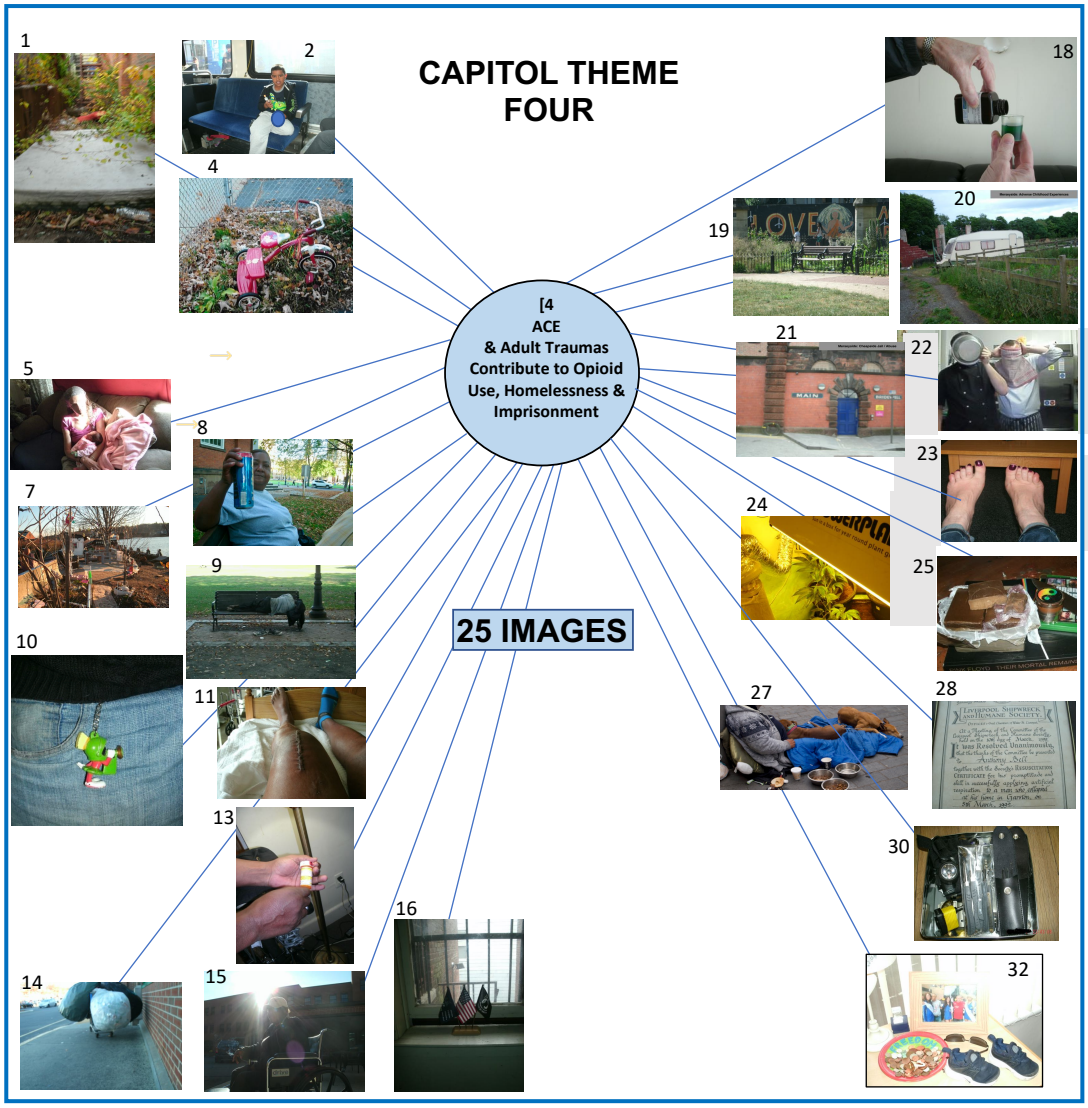


Figure 5. Capitol Theme Four and Associated Capitol Works

As acknowledged in Capitol Theme Three, there was significant overlap between the categories of relationships and adverse childhood and adult traumas as these two experiences coalesce around the fact that human

interactions potentiate different experiential responses and conversely, that lived experiences can potentiate a variety of human interactions. This *chicken-or-egg* analogy recognizes that ACE and relationships were impossible to fully separate with regard to the participants' lives as a whole.

ACE and adult traumas contributed in complex ways to participant opioid use through the accumulation of negative lived experiences that were predictive of opioid use and opioid dependency. Participants described experiencing issues of abandonment, assault, the death of a loved one, rough sleeping, broken relationships, chronic physical pain, social isolation and physical, emotional and psychological abuse which negatively affected their lives and predisposed them to illicit drug use. Formal ACE surveys were often a poorly understood health evaluation method among the New Haven participants, while participants from Liverpool had more experience and understanding of basic ACE surveys and how ACE scores are associated with mental health needs.

For the purposes of this study, estimations regarding the relationship between quantifiable negative experiential factors in childhood and adulthood and a relationship to long-term opioid use among the participants will follow the basic questions used in the Adverse Childhood Experiences Study (ACES) (Dube, et al., 2003). The study examined among other things, the relationship between an individual's illicit drug use and the categories of physical, emotional and sexual abuse, physical and emotional neglect, growing up with household substance abuse, parental discord and illicit drug use. At no time during this study were participants asked specific questions about these ACE categories or surveys, however the participants openly shared information about lived ACE and adult traumas. Research conversations were participant-led and details of individual ACE and adult traumas were not a primary goal of the photographic collaborations. Frequently during PGIE meetings, participants shared experiences that aligned with answers to ACES questions. Global Theme Four was the result of the unfortunate reality that the vast majority of participants experienced several characteristic factors from ACES which are known to increase the risk of illicit drug and alcohol use in both Liverpool and New Haven.

There were data early in the research that identified the experiences of abuse, neglect and family drug use among all of the early New Haven participants. As analysis progressed and further participant collaborations were conducted, the associations between ACES and the experiences of the participants revealed a direct and positive correlation with these older long-term opioid users in both cities.

Included here are seven participant quotes that convey a fraction of the many associations between problematic opioid use and the experiences of childhood and adult trauma among the participants.

There were many narratives discussing physical abuse and neglect.

"I just had a very difficult relationship growing up. there was a lot of child abuse in my, sort of, childhood. Physical, not sexual abuse like, do you know what I mean? And I sort of blame all my using drugs on that basically. I wish my childhood was, well it was all based around fear, humiliation, ridicule, no self-worth, no confidence, no trust in any sort of adult relationships and it was a nightmare." (GP, UK)

There were many narratives discussing adult traumas among vulnerable PWUD who were also homeless.

"I have been clean since 2 November, for 10 months. I'm proud of myself because I thought it was going to be hard, because when you relapse all the time like me, it is hard for you to go back up again. I relapsed because I told you, my husband died in my arms. He had an asthma attack and I still remember him every single day. I don't deny it. But as I said, I have to let him go and so far, I am doing okay." (LC, UK)

There were narratives discussing ACE and the need for young people to be educated about drug prevention strategies using the ACE family survey.

"There is always a reason why we all take drugs. It took me a long time to realize that I was on them from past hurt, past things, but I had to learn that myself. I was in my fool's world. You know, I'm learning that now. That needs

to be in place at a young age, and it needs to start in schools. Education is key. (CB, UK)

There were many narratives that discussed the experience of illicit drug use in the home and illicit drug use by family members.

"I got abused as a kid and I couldn't deal with that. And now these kids are coming up on drugs, with a mum and dad who were on drugs, you know, the way they're living now and the way the money is done. It's going to get 10 times worse and people just won't listen." (BW, US)

There were narrative discussions about the experience of social isolation, hopelessness and risk of drug overdose.

"I've been dead six times on different occasions. But I was just so self-centered at that time. I wasn't thinking how anyone else must feel. My father had long died and that decimated my mother, probably my brother and my sisters as well. And I had no thoughts about how they were. You know, all I could think about is why isn't anyone helping me." (CB, UK)

An unfortunate finding of the research was that all female participants in New Haven and Liverpool were physically, emotionally and sexually victimized from a young age.

"It goes back to my childhood. I wish I could say that the military is my excuse, but I am an incest survivor. I was predisposed to it and was molested by my cousin from the time I was eight until I was 12. And just before I went into the military, my grandmother died and […] I got introduced to cocaine. But I think I was vulnerable, and drugs were my way of anesthetizing the pain and not thinking about my problems." (DR, US)

There were narratives from homeless individuals who experienced healthy childhoods with stable family environments and suddenly suffered remarkable family traumas in adolescence which led to social isolation and depression.

"My father got murdered in Milwaukee, Wisconsin. He was on a business trip and I was 15 years old. They got robbed and shot. My father and another guy died […] He was married to my stepmother […] but I was not close to her and then everything changed for the worst." (RW, US)

There were narrative discussions about multigenerational physical and sexual abuse and the responsibilities mothers have for their children.

"And then [after immigrating to the US] I lived with my aunt and she told me about my mother. I never knew my mother. She killed herself when I was four years old. She was 26 years old when she died. I don't know if her father, who was my grandfather, raped her. My grandmother used to treat me like a piece of shit, because she never loved us females and she just had my mom and my aunt for girls. My aunt always told me that [my grandmother] was very physically and mentally abusive, and [my grandmother] abused me, too. My aunt told me that I look like my mother. I think my grandmother blamed my mother for, I don't know, for me. I think my grandfather raped [my mother] too, his own daughter. That's what I'm thinking in my head. That's why [my grandmother] blamed me when [my rape] happened." (LC, USA)

5.7 The Thirty-two Capitol Works

The thirty-two *Capitol Works* were the result of partnering the participant photographs with participants' narratives and experiences to explain and define the visual images to an audience. As stated previously in 5.1, the superordinate works are referred to as *Capitol Works* because they are structural in nature, house important ideas and principles, ethically represent the people of a particular society and support equity, equality and human rights. The superordinate themes developed here are referred to as *Capitol Works* because they are structural in nature, house important ideas, represent the people of a particular society and can be seen from a great distance as a beacon of light.

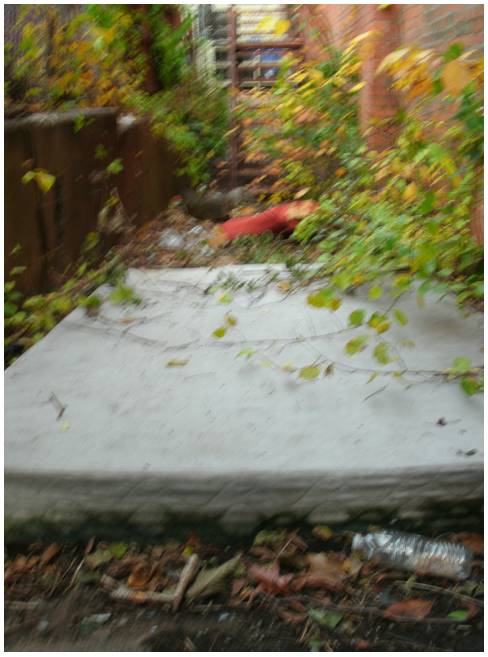
The thirty-two *Capitol Works* were chosen to document for the reader the most important issues discussed by the participants. In all cases, the discussions were used to inform the researcher about lived experiences and the meanings and intentions behind the photographs. In rare cases, the narratives from one participant captured the essence of another participant's photograph, while also strengthening the intentions of the participant photographer. This method of making meaning from combining the data from two participants was a novel approach and supported by the centrality of the researcher within the ethnographic environment. The researcher, with a deep understanding of all the data, all the participants and all the photographs was uniquely qualified to make these connections between the visual and narrative data and the experiences of the participants.

Image 1

Image 1: RT, USA

"It goes back to my childhood. I wish I could say that the military is my excuse. I am an incest survivor. So I was molested by my cousin from the time I was eight until I was 12. I was already predisposed to a lot of pain. And when I got older, just before I went into the military, my grandmother had died. And it was the first time I had been introduced to cocaine. And that was my greatest high in the world, until I got heroin (laughs) and then that became my greatest high in the world. But I think because I was so, so much in pain, and trying to hide it, that was my way of just, forgetting. It was my way of not being vulnerable and my way of anesthetizing the pain and not to think about it." (DR)

"And this is a picture of the mattress. Yeah, that's where the girls work. or the guys work. Now-a-days it is an equal opportunity mattress. That mattress is surrounded by needles. I didn't want to touch anything, but that's, that's part of the addiction. This is right behind the organic grocery store in New Haven." (RT)



RT walks by this lot nearly every day. It is an example of the conditions and the socially accepted behavior in New Haven. RT and DM are veterans who often described the differences between the poor quality of treatment of New Haven's homeless drug users versus the wide availability of services from the West Haven VA hospital.

Image 2

Image 2: MR, USA

"I got abused as a kid and I couldn't deal with that. And now these kids are coming from drugs, with the mom and the dad who were on drugs, you know the way they're living now and the way the money is done, it's going to get ten times worse and people won't listen." (LF)

"I always worry about getting shot. Like right now. And we can't do nothing about it. That's our park." (LC)

MR took this picture while on the New Haven bus. He knows the mother of this child with a toy gun and handcuffs. He got permission to take the picture. He does not think the mother is a good mom. There were other pictures taken on the bus which led to deep and meaningful conversations about New Haven.

Image 3

Image 3: OS, USA

"He started (his business) at the beginning of the summer. That's what he's doing now. I have known (him) for a couple of years. I think I met him back in 2014. He first came down here from New London (CT). He was on parole. Then they packed him in, and he did like about a year and he just got out again a few months ago. And he's been doing that since about the beginning of the summer, but the Green has its conflicts. There are some conflicts out there." (LC)

OS had a friend take this picture. OS has a wide social network on the New Haven Green. He considers himself a businessman selling drinks and snacks to people changing buses beside Yale University Campus and New Haven Green. His dream and the content of some of his pictures was to buy a food cart, food truck or food trailer. His dream is to expand his business to a retail shop. OS used his photographs and camera to try and secure a business partner for expansion.

Image 4

Image 4: CL, USA

"I know people that have been on a housing list for two years. That's how bad housing is. And it's not just the addict who needs housing. It's young mothers with kids who need housing. When I was in Los Angeles, the waiting list was 10 years. {…} And here I don't know how long it is, but New Haven is not that big a city. {…} God knows how long they will have to wait. It's terrible." (BG)

CL took this picture in her front yard. She was the only participant to be a homeowner. She inherited this house. She lives with a boyfriend, son and a granddaughter.

Image 5

Image 5: LB, USA

"Grandchildren give you another chance to fix whatever mistakes you have made with your own kids. A lot of the times, through their whole lives they used drugs and were never around for the kids. Its in the past because you can't bring the past back, but you could fix the future. So what you didn't do with your kids; you try to be a better role model for your grandkids. Better you're telling them what the street is about because you were on the street. So like my kids, I told them what cocaine looks like and I showed them what weed looks like and what pills look like. If you go to a party and you lose sight of your soda, please leave your soda. Buy another one. A new one is not going to kill you but maybe if you drink that one it will. But your grandkids are something that you do different. You try to fix whatever it was you couldn't do different with your own kids." (RL)

This photo of LB was taken by her son, the father of this baby. There are at least 7 people who live in this rented house. LB is HIV positive which qualifies her for special housing benefits that have provided this rental for several years in New Haven. LB also qualifies for home health services which include a nurse who brings her medications and provides nursing care and social services a few times every week. She is allowed by the state to share her home with adult family members.

Image 6

Image 6: RW, USA

"I don't care if it is in a shelter. Your ass isn't sleeping outside for the night, but they're just not ready to go home. They'll wait until later and they make excuses. And you know damn well those (shelters) aren't letting you in late at night. So, I wonder what they think about? When you're laying out here on a cold bench, people walking past you, you don't know what they have on their mind, but what is most important is the police riding by will wake your ass up and tell you to get the hell out of this park and, don't let us see you here again nigger and then that's when you have to make the choice of your life. Would I rather go through this or would I rather be in jail? Being incarcerated until about the springtime, just to get somewhere warm to stay and something to eat. It's just the monotony all over again and as soon as they move them out, another person moves in. As soon as they get rid of him, somebody else moves in." (MR)

This photo was taken by RW on the New Haven Green where a local group is providing free clothing for all. RW had many friends around the neighborhood. At the time of this photo, RW was living in a few different abandoned buildings in the neighborhood and also sleeping in a friend's motorhome when she was parked nearby. RW had many friends and took the researcher on many adventures through the neighborhoods.

Image 7

Image 7: RL, USA

"When somebody is homeless, the only thing that they can turn to is drugs, because that's how they are going to meet people and get into people's houses you know, if they get involved in drugs. And that is how they're going to make extra money to be the lookout for the cops, or be the runner for the drug dealers, you know. Go take this someplace else. Bring this, bring that. That's the only way that they can make money. Because if a homeless person was going to an office to apply for a job and he has dirty clothes they're not going to give him a job, but drug dealers don't care how they come to work. You could come dirty or you can come clean but you're still going to do the same thing. So, a lot of times they have addictions. A lot of time people are homeless because they have addictions." (RL)

RL took this photo, along with many others on the banks of the West River that snakes through the western edge of New Haven. The area was historically used for manufacturing and has since been abandoned, stripped and condemned. There are many facilities in this area that are no longer economically viable because of contaminated soil and pollution. This area is well secluded, making it a peaceful and beautiful area without the problems that occur on the New Haven Green.

Image 8

Image 8: RAF, USA

"New Haven is a silly, sad city. They don't help the people here. They're not alive. To me, I came out of jail here with nothing and the thing is, my circle that I run with, or my people or whatever, particularly they have problems here. There are many things wrong and now this drug shit. That's even compounded even more problems. The violence and homelessness. Some people don't just give a fuck after a while. People don't. And when you are out on your own, it means everything, you have to have an address. (OS)

This is a photo of a woman, but here in the park, she is referred to as a man. She is not a member of the bench friends, although she uses the same bench as the crew. She uses the bench because she cannot be intimidated to leave. She is friends with a person that the bench crew call, Transvesty. Overt racism, sexism, bullying, victimization and discrimination are accepted / tolerated in and around the New Haven Green. Often issues between people become physically violent. This woman has a reputation as a good fighter.

Image 9

Image 9: BG, USA

"Why can't we waste a little time helping these people to educate themselves. It is like being born again. It is like when you're a kid and your parents teach you how to cook, they teach you how to clean and they teach you how to fold your clothes. You have people who haven't been housed in 15 or 20 years here. They don't know what to do. If you give them a corner they know how to curl up and sleep. Like as if they were animals. We had a guy who was sleeping homeless for four years and he was sleeping in a bathtub. It took him almost a month to get out of the bathtub because he was used to that confined space. " (RL)

"Well right now, I'm basically homeless. Last night I slept in an abandoned building. It was sheltered inside, but it's vacant." (RW)

BG is a veteran that frequents the area around the New Haven Green because he uses the bus to travel from home to the Veterans Administration Campus in West Haven. He stressed the significantly different experience he has at the VA hospital and the experiences of non-veterans who sleep rough on or near the Green.

Image 10

Image 10: RW, USA

"If you have a hundred homeless people using any kind of drug, alcohol, heroin, K2, weed whatever you think, out of 100 people, I would say 85% are doing drugs because they're homeless and it's easy to get." (MR)

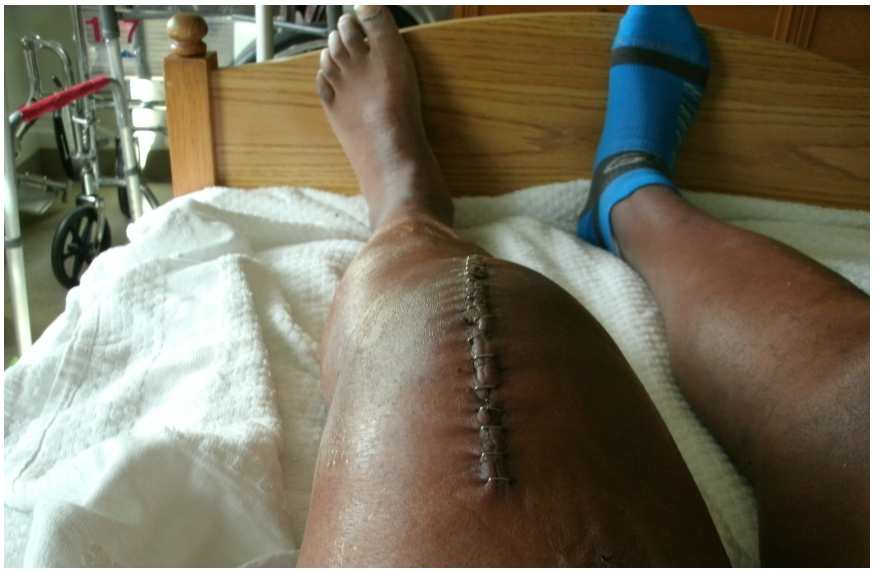
"My father got murdered in Milwaukee, Wisconsin. He was on a business trip in 1979. So, we came back to our family back here. I think I was like about 18. Maybe 17 or 18. And I have been back here ever since. He was on a business trip and he got robbed, he and a couple of his colleagues. They got robbed and shot. My father and another guy died, but one of them survived. He was married to my stepmother at the time. He remarried. I but was not close with her and then everything changed for the worst." (RW)

RW took this photo in response to his brother's kindness and his long family history in New Haven. RW chooses to live on the streets because he has a deep mistrust of the shelter system and strongly protects his independence. This is the key to his brother's home nearby. This cartoon martian represents a connection to family.

Image 11

Image 11: BW, USA

"Some guys get a lot of pills. They're charging anywhere from, well if you're selling a 10 mg Percocet you're going to get $10 and if you have a 90 mg then you're going to get 90 bucks. some guys get 90 Percocet pills for the month and they sell them all." (DR)



BW became a participant at a time when he was unexpectedly scheduled for a knee replacement at the VA Hospital. He described himself as suffering from opioid dependency related to prescription pill use for years. BW had significant stress and anxiety about going in for surgery and not being able to take pain medicine. He took many pictures of the staff and the food and the services in the hospital and stressed how lucky he was to have had so many surgical procedures and services because of his veteran status. He has new hips, knees and shoulder.

Image 12

Image 12: MR, USA

"I got introduced to opiates by friends. Peer pressure, I guess. I got introduced to heroin the first time was out there in LA. Out there in high school, I was experimenting. I experimented with it a few times. But I didn't really get into it until I was into my late 20s or early 30s. I went through a few years of using. I was using heroin, percocet, oxycodone, methadone. I was buying it off the streets. I have never been on a program." (MR)

This is a photo of LC and MR on the Green. This group represents friendships and frenemies, drug use, sobriety, and relationships. The next bench, 30 yards away, is the K2 bench. During this project there was a two-day period when over 100 people overdosed on free synthetic cannabinoids, the result of a new drug dealer coming to the Green and giving away free bags. This group spent that time sitting on the bench and watching people overdose beside them. Nobody from this group used any of the free bags of K2.

Image 13

Image 13: DR, USA

"My thoughts on all the drugs that are out there is that they help some people. Suboxone I didn't really like. I think I had an allergic reaction to it. It made me itch too much, but I know people that it helps. It keeps them off the heroin. I took suboxone mainly for pain. I took it a few times, but methadone helped me better. It's a good drug for helping people. It helps a lot of people stay off the heroin. (BW)

The veteran's hospital requires people taking this type of medicine to participate in random drug testing because there is a potential for people to sell pills to supplement their income or use illicit drugs in addition, which violates a medical agreement (pain contract) for these types of medications. This picture represents both physical pain and cash.

DR is a veteran. This picture was taken because of the red label on the top of the bottle. DR said that there was stigma associated with the red label because it was a class A drug. Others see it and know what it is.

Image 14

Image 14: RT, USA

"I asked that guy if I could take a picture of the shopping cart (recycling) and he said no problem and that's how I make my money. That's how he makes his money, and I can just come up here (to the VA) and go to the psych emergency room and say that I need help, but that's how he supports himself. {…} Unless he is a veteran, he's got nothing. He's got no chance. He really doesn't. That's what I tell these guys. We are lucky. We are lucky to have this place. I say that almost every meeting at least once a week during one of the meetings I go to. We are very lucky." (RT)

RT took this picture to illustrate what other people who are not veterans must do to survive in New Haven. These are aluminum cans that can be returned to local grocery stores for cash. In CT, the return is $.10 per can. This cart represents a considerable amount of money and work.

Image 15

Image 15: BG, USA

"It's going to take a little while longer, but all these pictures to me, meant something to me. I'm here with the groups and some of the nurses, and some of the rehab sisters, and I didn't get to take as many as I wanted to, but all these pictures have some significance. But my life is like that. I don't have a lot going on. I don't have a lot going on in my life." (BW)

BG took this picture of a friend who also has veterans benefits, but continues to smoke cigarettes and use drugs. The subject of the picture has multiple comorbidities and gets good healthcare services from the VA but has depression. The friend is often misidentified as someone who is homeless, but he lives in New Haven in a group home and manages to get around the city in his wheelchair, despite his health conditions.

Image 16

Image 16: BW, USA

"An opiate user over 50, if you're just an opiate user, it will probably get too expensive at some point and you'll have to stop. But if you're an opiate user with chronic pain, then if you don't have the surgery or the docs don't try to help you with your pain, at some point the pills get so expensive that it just becomes easier to go and get a bag of dope. That's how a lot of people transition from pills to heroin, but the community doesn't ostracize you when you're over 50. They have their own worries." (BW)"

BW took this photo after moving from his apartment with his mother, into a place he could be proud of. He considers himself to be different than the individuals who use drugs in New Haven because of his experiences in the military. He believes there are things that veterans can only share with veterans and civilians cannot possibly understand how to properly support somebody like him. BW believes the difference in treatment options are very different for veterans and people who use drugs in New Haven.

Image 17

Image 17: JO, UK

"It's about looking at the mindset of somebody who believes that their place in life is to sit on a wet floor, a wet cold floor and beg people for money. And for me I think this is something that opiate addiction generated or degenerates into. That state of mind. I see it in other addictions like alcoholism but I think (heroin users) live a different sort of lifestyle with a different mindset. People who predominantly are opiate users come from a place of not being good enough. " (CE)

"I think that's the next step is to sit on the floor and just hope that somebody will rescue you in some way. Because it is it is all about your mind. " (CE)

JO explained this photo several ways.. This photo was taken in Liverpool City Centre. Although this building has become a restaurant, this structure continues to provide rain protection and continues to be a common place for rough sleepers to protect themselves from getting wet. Most nights this spot is taken.

Image 18

Image 18: PJ, UK

"Nearly for 12 years I was every day back in the chemist's. They didn't trust me to take my methadone medication home. And I was mistreated every day I went there. Every single day I was looked at as a smackhead. It was like the people who were coming in- because you're on a script it's a totally different colored script it's a green script. So people know that's a drug addict. So, when they come around you, they have to bring it because they have to sign for it when you take the methadone. The pharmacist has to sign it and it gives them a lot of control. So, everyone sees that. And I'm 50 and I've got to stand in a shop and take medicine like that? Fuck off. Do you get me? That's why that was done. That's what people have now to do every day. So that was my prison. And that's why I took that picture. It's terrible right? Boots (pharmacy) is a prison." (AA)

PJ took this photo, to help with discussions about his decade long use of methadone as a stand-alone remedy for opioid dependency, a practice common among older opioid users in the UK. This type of treatment is used less frequently in the US and for a shorter duration.

Image 19

Image 19: PJ, UK

"I haven't been in jail for a few years now, but now, they know you've had a drug addiction.{…} And just before you get out the care workers in the prisons are there to see where you're at. If you don't want to get clean you can't force it. They would actually say to you, where you at and where you going and what are your plans? {…} You can say, I was hoping to get some treatment and then they will post the way to try to get you into treatment. We're really fortunate. I think people coming out of prison and suffering an overdose has really dropped in this country." (PJ)

PJ took this photo to explain a time in his life when he wanted to go to jail. He walked across the street to a store and stole a large bottle of alcohol in front of a security guard, in the hopes of being arrested. He walked out and sat on this bench and drank the whole bottle, but the security guard never called the police. So, after drinking the bottle, he threw the empty bottle at the front doors of the store, breaking both the window and the bottle. PJ was arrested and taken to jail moments later. This is the bench. The event occurred over 15 years ago. PJ is enjoying his years of sobriety.

Image 20

Image 20: GP, UK

"When you use drugs, and do the things you do, you end up pushing everyone away. You end up with nowhere else to go except living on the streets. The hospitals won't have you back. So I'd end up in hostels. And as a result of using in the hostels and abusing the hostels they banned me, so I had nowhere left to go but the streets. That's how I feel. Drugs and alcoholism are intertwined with homelessness because that's where you end up. That's a fact. I don't know anybody that used like me, that didn't end up in that place. Everybody I used with down in {there}, we all ended up on the streets and most of them are dead now. (GP)

GP took this picture along with a picture of a lock-picking set and his heroin using equipment. He explained he used the lock picking tools to break into caravans like this one to buy drugs. Sometimes he sleeps in the caravans, sometimes he uses drugs inside them, sometimes he just steals items from them.

Image 21

Image 21: PJ, UK

"When heroin first come to Liverpool, I was using heroin for 12 months before I even realized what it was and that was the same for a lot of people that I know. Nobody knew when things first started all smoking heroin, we didn't know we were going to spend most of our fucking lives in that and in and out of prison and in bad places. We didn't even dream of that." (JL))

This is a picture of Bridewell jail, which has been closed for many years, now a hotel. PJ was arrested and taken here, handcuffed to an iron ring and beaten by police. He spoke of a famous police officer who was named Handlebars for his large mustache. Handlebars beat PJ while handcuffed to the ring and also showed PJ a picture of a doctor, telling him, "you wanted to see the doctor, here is the doctor", while laughing at his heroin withdrawal symptoms. News from the era suggests there was an infamous police officer named Handlebars, possibly still alive today.

Image 22

Image 22: JO, UK

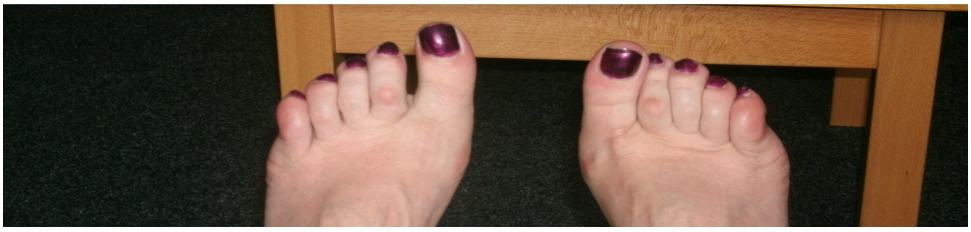
"The opportunities have passed you by by the time you get to 50. For somebody like me I had never worked, I left school at 16. I was a heroin addict just after my 16th birthday and I spent 28 years in active opiate addiction. My brother is still in opiate addiction and he has just turned 50 at Christmas and you know, he is skint. He has nothing really. So the people who are living like that, they don't have any opportunities. They have no resources. They feel like they don't have any skill set to fall back on. And a lot of times by the time you get to 50 and you've been on opiates all them years, you feel like you have burnt all your bridges with people because you have absolutely tapped people up to death for money. You've lied. You've stolen. You've deceived people. So I think it is a very sad hopeless place to be." (CE)

After years of being unemployable due to heroin, JO returned to a job in a restaurant that has permanently closed due to funding and coronavirus. He truly loved both his job and the people he worked with. JO credits his sobriety with being part of something bigger than himself. He credits this job with giving him several new tools to help others and do his job well. These fellow employees are aware of his participation and agreed to pose for his photo.

Image 23

Image 23: CE, UK

"I have grandchildren {…} and they are a huge part of driving me forward and to make amends to my daughter for her life. The love that I have for them is limitless. It has no bounds. I adore them. But there are many layers to it. I'm doing it for (my daughter) as well. It's just a different love. And being clean, my (grandchildren) have never even seen me smoke. They have never seen me take a drink or a drug or anything like that. I am just their Nan. They see me as some sort of hippie. I'm some hippie who's dead loving, and dead kind, and when I'm with them I just adore them. I think when they were small, I still had this like, low self-worth and low self-esteem. {..} When the kids come to me, I would sometimes think I don't know why they want to be here with me. I don't even have WiFi, just a little tiny house, but they prefer to be with me. And I think it is because of the attention I give them and the love. I don't have a large telly and I don't have all sorts of PlayStations and stuff, but it is the love that I am able to give them. I had never felt like that until they were born. I had never felt like that as a mother. It's powerful stuff isn't it? (CE)



This is a photo taken by CE to show her active changes in how she lives life after long-term heroin use, her effort and approach to self-care and how looking after yourself is the first step in looking out for others. All of CE's photos were happy and positive. Her newfound sobriety has led her to participate in helping others to accept their drug use situations and work to better themselves with peer assistance from NA and AA.

Image 24

Image 24: JL, UK

"It's the cash machine of organized crime that, growing weed. They're doing it all, selling the smack and the coke, but they all got them plants growing. It's like the ATM. So the police target them because they've got guns and they're shooting people, but they're not going to target me. I'm not doing no harm to nobody. {...} Liverpool is just full of it. Every single mother will have one (plant) in the bedroom, the spare bedroom." (JL)

JL took this picture because he is proud of participating in growing cannabis and because he makes money from the sale of cannabis. He sees nothing wrong with selling cannabis, although he admitted that if his parents had smoked cannabis when he was a teen, he would have left home. He said he'd have resented their pot use. He grew up in a normal home and was changed by the sudden death of his older sister, who was a rising musician in the 1980s music scene in Liverpool. His brother is a member of a local Liverpool gang, which also bring JL a sense of pride.

Image 25

Image 25: JL, UK

"I was parked on methadone for years, from 1989 when I got out of prison, and I was a kid, I was supplying drugs with my partner. I didn't know what methadone was before I went in. There was no such thing as methadone as far as I was concerned. there was just smack. I was parked on methadone from 1989 until 2010. It was 20-odd years I was on methadone. I used to go to my counselor or my drug worker for Methadone and they would ask if I had been using, and they would say that if I stopped using smack they would up me on my methadone." (JO)

JL took this picture of what was described as 7 kilos of hashish. The brick was cut with the knife beside to make sure the kilo was solid drugs. The grinder was in the photo was because the hashish must also be smoked to ensure authenticity. JL says UK drug distribution is lucrative, much more so than a regular job.

Image 26

Image 26: CB, UK

"I've managed licensed pubs and clubs and bowling alleys in my past and I was sacked from a number of them until I became unemployable, because I had an addiction. So I had the skills to do this, but when I first went into recovery, I didn't think I was able to do it. It took me a number of years to build myself up, because I had the skills for managing but because I had previously managed by threatening staff and promising them things that may or may not be delivered. So I didn't think I could ever be a manager again. But when this became available, I thought this is something that I could manage. {…} It feels like all the skills that I've gained in my life up to date we're perfect for coming to work here as a manager." (CB)

CB took this photo to show his return to management. Although he spent many years using heroin, he credits LFC with getting him off heroin use. He started traveling throughout the UK to support his team. He needed money to travel, so he started working more than using heroin. He felt like he was again part of a family, since his drug use broke many of his relationships. Following LFC gave him new friends who didn't use heroin, which helped him move from one social group to a different social group without heroin.

Image 27

Image 27: PW, UK

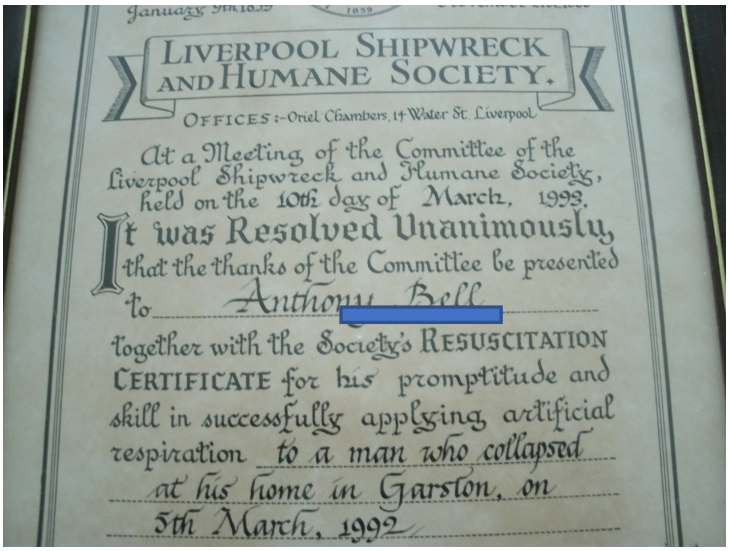
"I've been dead 6 times on different occasions. But I was just so self-centered at that time. I wasn't thinking how anyone else must feel. My father had long died and that decimated my mother, probably my brother and my sisters. And I had no thoughts about how they were. You know all I could think about is why isn't anyone helping me." (CB)

PW and CB both spoke frequently about understanding the plight of those asking for change in Liverpool City Centre. This photo was taken in Liverpool City Centre. Some people who ask for money in Liverpool believe that having a dog with you makes you more money because people like dogs. Others believe that dogs are better friends than people. In this picture, the photographer believes that this guy, an acquaintance, is a true dog lover, evidenced by the good condition of the dogs, the bowls of food and the collars.

Image 28

Image 28: CB, UK

"When I first got took to AA, I thought I would be better suited in Narcotics Anonymous, but the person who came took me to AA. He strongly believed in AA. And when I went there I didn't use or drink for the rest of that day. And initially I was just getting support from other people on a daily basis and I would go to meetings every day and every night. But what changed my life was working the 12-step program. And being able to connect to myself and to some other people- call it God, and just participate in a program that allows you to connect to your best self." (CB)



CB took this photo, proud of his family. He has repaired broken relationships with his mother and his brothers during sobriety. CB continues to live in Liverpool.

Image 29

Image 29: PT, UK

"You do have more options haven't you, because you have your (younger) age advantage. But when you're like a certain age, it's harder. It's harder to get out and make money. It's harder to get employment. Life just becomes much harder for some of these people. Don't ask me why, but it does. So, what happens then, is like you sort of give up on yourself as well. Because you've got no money and you don't think you're ever going to have money because life has passed you by. It's that kind of attitude. I have seen that. I have actually experienced it." (DM)

This photo was taken in Liverpool by PT. This church garden has always been a place for retreat from the busy streets around the cathedral. It is very secluded and very removed from quickly calling for police. It is also one of the prettiest parks in the area. PT knows it as an old place where he and friends came to use (gear) heroin.

Image 30

Image 30: GP, UK

"Heroin habits I can keep down to 50 or 60 pounds a day. Sometimes 20 or 30 pounds a day, depending on the strength. But I spend a lot of money and it's hard to find and it's hard to pay my bills and live and all that. So you're forced to become a criminal. Or girls become working girls. These are my tools for getting in, I'm not proud of the picture, but this is my life." (GP)

"Life just becomes much harder for some of these people. Don't ask me why, but it does. So, what happens then, is like you sort of give up on yourself as well." (DM)

GP was open with his use of drugs during collaboration. He lived in stable, but temporary housing in Liverpool and had a pet dog. GP said he was a carpenter by trade, but wouldn't be good at it while he was using heroin. GP was always on time, worked to educate the American researcher on drug culture and may have had the largest collection of photos of any participant in Liverpool.

Image 31

Image 31: PJ, UK

"Grandchildren don't make me stay clean. It's a thing that I stay clean for. I don't want to ever let my grandkids see me using, like my kids did. And that's a big driving force in my recovery. My other daughter has just become pregnant, so she's going to be having a baby in September. Oops I'm lying, in July. So, I'm happy about that. Here comes another one (arms raised cheering)! And I can be there for them like I could never be there for my own kids. I was in jail when one of them got born. And for the other one I was fucking using smack. I went to the hospital and I embarrassed them. It just wasn't good, but now as a result of it, I'm clean. I can be a proper grandparent and it's great that we can just give them back. Do you know what I mean? (PJ)

PJ spent a considerable amount of time discussing his and his many family members' drug dependency, including his son and his daughter-in-law. The result is that he gets to see more of his grandchildren and make amends for the the problems he caused for his own children. Grandparenting was a significant theme among many of the participants. Grandparenting was said to connect family in a different way than parenting your own kids. Some referred to grandparenting as a way of getting another chance to make things right.

Image 32

Image 32: JO, UK

"That's my grandchild, I was playing with him this morning because I don't get to see much of him now. His mom has just come out of rehab. His mom is a cocaine addict. She is an addict. And she has realized that she has a problem and her relationship is on the rocks. She has 3 kids and all that. Kids don't keep you clean as I know. As I know, kids will not keep you clean." (JO)

This is a picture of JO's bedside table, showing his grandson's shoes, a tray of coins, sunglasses and a proud family photo. JO has been opioid and alcohol free for several years. He credits his sobriety to AA and opening doors to connections. JO's photos were often about relationships and isolation among the same group of people.

5.8 Photographs of Rough Sleepers Connected to All Capitol Themes

Nearly all participants took photographs of rough sleepers as a way to make an early association between opioid use and the issues of broad homelessness. Representing more than a lack of housing or shelter,

participant photographers directly associated their images with problematic opioid use and critical hardships. The participants universally described rough sleeping as an end result of drug and alcohol dependence, an outcome that a percentage of PWUD have difficulty escaping. On many occasions the participants discussed how problematic opioid use, broken social connections, lack of resources and the risk of being arrested, compounded the problems associated with rough sleeping. This four-factor problem was a common subject in conversations in both Liverpool and New Haven, although in Liverpool the stories were more historical from years past, while in New Haven the stories were described as long-recurring or more recent events. Photographs of broad homelessness were connected to descriptions of polydrug use, mental illness, hopelessness, depression and isolation. Conversations about photos revealed how safe, stable, permanent housing was necessary for physical and mental wellbeing and how problematic drug use and drug dependency prevented individuals from maintaining a steady connection to people, meeting their personal needs and accessing local resources. Conversations about rough sleeping photos led to discussions of all four *Capitol Themes*. Conversations about family relationships, isolation, hopelessness, depression, discrimination and racism were often intertwined with rough sleeping photos.

Conversations within both cohorts made known their beliefs that most rough sleepers in their respective cities, were individuals they suspected of having a *dual diagnosis*; problematic drug use issues and mental health needs which were both unmet. This widely held opinion was informed by their collective experiences with broad homelessness, rough sleeping, broken family connections, long-term opioid use and mental health services.

> *“It's because you start to feel like I have nothing, or I am nothing. I might as well kill myself. I believe that if I didn't get clean and I was still homeless and living on the street, I would probably still be using heroin. I really would because there is something about giving someone something to be proud of, a home. A home keeps you wanting to hold on to that. But when you are on that bench*

and it is cold, and people are walking by and they don't have nothing and you don't have nothing, it is very easy to stay in that world. It really just is. It's really easy and that's why I'm grateful every morning, I wake up in my assisted living home. Because I have slept on a bench. I, too, have walked in the snow with slippers on. I have done all of the things that you see in those pictures.

Rough sleeping and its association with problematic drug use was a universal belief of the participants, but opinions about the causation of an individual's drug use varied widely. All twenty-five participants had personal experiences with concurrent problematic opioid use and broad homelessness over years, although the causes, duration and severity of housing problems, varied widely. Professional services for housing assistance and health problems were discussed frequently and found to be significantly more available to the Liverpool cohort, as local drug services and GP practices and in rare cases, law enforcement, offered ways to connect people in need with assistance and health care services. In contrast, access to GP practices and drug services in New Haven were less available or unavailable, had substantial wait times, often had associated fees for services and subjected those in need to stigma and discrimination from health workers, law enforcement and shelter/housing staffs. As indicated previously, periods of rooflessness and rough sleeping were reportedly longer in duration for the participants from New Haven, in part due to local regulations, lack of affordable community housing opportunities, lack of shelter beds, insufficient access to healthcare, lack of money and broken family relationships.

5.9 Photographs of Family Connected to All Capitol Themes

Participants frequently took pictures of friends and family, as roughly half the photographs discussed contained people. Often, the camera was used to share and connect with others through the novelty of taking photographs within different social networks. Participant photographers used the cameras in

different ways, some to improve their social standing in multiple environments, some to make art, some to gain control over impulsive behaviors and some ventured outside their comfort zone to accept both praise and criticism from friends, family and peers regarding their photos. It was the opinion of the researcher that all the participants gained positive self-esteem from taking and sharing their personal photographs an enjoyed participating in the research collaboration.

Children were a very popular choice of photographic subject as they tend to make for youthful and happy photographs and rarely do kids hide from the camera in the same way adults tend to behave. There were photographs taken of sporting events, religious services, activities in the home, activities outdoors and group events with nearly all the photographs also containing people. When asked who the people were in a particular photo, the conversations would often turn to introducing their photographic subjects by name and informing the researcher about how they were connected to one another. These images almost always captured a family member, not always biologically related, but they were intimate partners, long-time friends, offspring and frequently, grandchildren.

One female participant from New Haven chronicled in photos, her weekend with her grandson and was one of the first participants enrolled in the study. She shaped her first collaborative conversation with the researcher around the subjects which she loved. The thing she loved the most at that time was her grandson, who was a teenager. She had been open with her family about her long-term polydrug use for two decades and had broken their trust countless times, but she was proud of her last 3 years of (nearly) drug-free living and her reconnection with her adult-aged daughter and her grandson. She found joy in getting the opportunity to spend time with her grandson in a way she did not experience with his mother. There were photos of him playing basketball, football, running track and lifting weights. There were pictures of him cooking and dressed up handsomely for church services. Her photos and interviews were some of the first in the research study.

> *"In one of the pictures you can see that I'm on the football field. Sitting there freezing. To support him. He is really the center, that makes the rest of this possible. …we get a chance to get it right the second time. The second time around."*

> *"We are extremely close. We are really tight. my grandson calls me "gr-homie". which is, I guess the short name for grandmother and homie. And I am his big toy. He will be graduating this year. He turns 18 on the 21st of this month. He will be graduating and hopefully going on to college. He hopes to be doing football and wrestling. He is infectious. He's just, he is infectious. "*

Because the researcher's first collaborative participant believed grandparenting was such an essential component in her recovery process, an unconscious decision was made to ask other participants about children and grandchildren. This issue of how grandparenting contributes to healthy behavior expanded throughout the conversations and eventually became a research theme for evaluation in both the Liverpool and New Haven cohorts as each participant gravitated toward unintentional grandparenting conversations.

Broken family relationships were also a nearly universal theme drawn out from the photographs of family, more so due to conversations about the people who were missing from the photos rather than the people in the photos, which provided evidence of how photo elicitation can reveal much deeper meaning from participant-made images. Participants expressed remorse for the damage they were responsible for bringing into the family and regretful for the unintended consequences that resulted from problematic drug use and the behaviors that led to alienation. Many talked about experiencing guilt related to broken relationships with family members who passed away before getting an opportunity to make amends for their behaviors.

> *"When you use drugs, and you do the things you do, you end up pushing everyone away from you and you end up with nowhere else to*

go except living on the streets because the hospitals won't have you back anymore. This is my experience. I ended up with my drug addiction, being in a part of England where I'd used gear (heroin) a lot, well I pushed them family and friends away. So, they wouldn't have me back."

5.10 Chapter Summary

This Chapter began with an introduction to the systematic methods used for the development of four *Capitol Themes* and thirty-two *Capitol Works*, using the MIEF and TNA frameworks. The four *Capitol Themes* were discussed in detail to document the associations, divergences and nuances between the photographs, narratives and lived experiences of the participants.

Additionally, the thirty-two *Capitol Works* were presented to demonstrate the clear associations between the photographs, narratives and lived experiences of the participants while strengthening the trustworthiness of both the MIEF and TNA to uncover the deeper meanings behind the participants' photos

Lastly, this Chapter also detailed the overlap, divergences and nuances that exist among and between the photographs, narratives and lived experiences of the participants and most importantly, how the presence of an experienced and learned researcher at the center of the data is uniquely capable of articulating the deep meanings within photos, stories and experiences while confidently providing answers to the research questions.

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Chapter 6: How Research Methods and Research Findings Answered Research Questions

"Photography is the truth if it's being handled by a truthful person" - Don McCullin

6.1 Introduction

This chapter serves to address and explain the notable research findings that were developed through the processes of both thematic and visual analysis. Participants from Liverpool and New Haven had over one hundred conversations with the researcher about their images and shared many personal opinions and perspectives regarding their health and the issues encapsulated in the *Capitol Themes* and *Capitol Works*. For the participants to convey the ways in which the images and narratives were associated with the health of older people who use drugs in Liverpool and New Haven, they introduced their personal living spaces, the conditions of their home environments, their interpersonal relationships with family and their social networks. To discuss these associations between themes using their photographs and experiences, the participants' needed to trust the researcher while the researcher needed to prove to the participants that the researcher understood broad homelessness, social networks, prescription and illicit drugs and health as they pertained to older peoples' long-term opioid use and recovery goals. This research framework incorporating the researcher's nursing and public health expertise, the thematic and visual methods used and the participants' willingness to discuss their experiences with opioid use were well suited to meet the ethnographic research goals of this study.

This Chapter explains how the MIEF, incorporating both thematic and visual analyses, was successful in developing research findings to answer the research questions.

6.2 Using an Ethnographic Approach to Answer Questions About the Experiences of Older People Who Use Opioids

Ethnographic research is often rich with ethically and politically uncomfortable situations where unexpected and unpredictable events can lead to a better understanding of a participant's lived experiences. Twenty-five vulnerable older people were recruited to discuss sensitive topics and share their experiences as experts of their culture. The researcher's credibility within the research study was not inherent; from the first introductions to gatekeepers and potential participants, the researcher needed to be considered trustworthy and non-judgmental while conveying genuine interest in the lives and experiences of the collaborators. The researcher connected with potential participants by displaying an appropriate sensibility to their stories, analytical attention to their lived experiences and critical self-awareness to the interactions, behaviors and unexpected challenges that materialized during the collaborative process.

However, being an *outsider*, more than any other single characteristic, was how the researcher was identified by the participant photographers. The researcher knew none of the gatekeepers nor participants prior to enrollment. Being an outsider among the gatekeepers and participants had its advantages and disadvantages, but researcher credibility was established by conveying to the collaborators, a genuine research interest in people who use opioids by a kind and compassionate nurse with experience in public health research. The researcher spent months talking with and listening to participants to understand more about their interests, overall health status, history of drug use, relationships, willingness to educate the researcher and their willingness to take pictures of their lives and environments.

From this inquisitive outsider perspective, it was possible to conduct emic ethnographic fieldwork. Ethnographic fieldwork exemplifies the basis by which researchers make sense of what is going on for a particular group of people: to understand the perspectives of both individuals and specific groups, observe culture and cultural identities and examine complex social behaviors

and processes. Ethnographic studies strive to contextualize a group's history, the historic events of the past, the institutional forces that hold power over individuals or groups and learn how culture and the structure of everyday life contributes to the health of individuals and communities. This challenge was was accomplished in this study by intentionally positioning the single researcher at the center of the entire analytical process and modifying Drew & Guillemin's Interpretive Engagement Framework for use with vulnerable older people who used drugs and were considered experts in opioid use in Liverpool and New Haven.

The findings are the result of a researcher-centered, ethnographic investigation that connected every interview, interaction, invitation and collaborative experience directly to the researcher. The researcher successfully developed personal connections with the participants and was well prepared to address unexpected challenges with analytical attention, flexibility and kindness. The researcher was well prepared to experience ethically challenging and important moments while using those opportunities to uncover a deeper understanding of lived experience from the participants.

6.3 How Unexpected Challenges and Reflexivity Served Ethnographic Goals and Led to Deeper Understandings

Reflecting on the ethnographic process, there were many experiences that required ethical competencies by the researcher as intimate details and emotionally revealing moments required safe and wise decision making. For instance, the first male participant in New Haven was living at multiple shelters during the five-week interview process and often asked for money from the researcher at meetings. While this may have been an easy request to fulfill, the exchange of money would have changed the dynamics of the researcher-participant relationship. His request and all subsequent requests from other participants were always politely denied. As a compassionate nurse and public health street worker, these decisions were emotional for the researcher as the serious financial needs of each participant were clearly evident and their

requests for money were minimal. To compensate for not giving money to the collaborators and turning down their requests, the researcher would invite participants for coffee or tea during interviews. The researcher carried cigarettes to share and was known to share homemade sandwiches or snacks when visiting parks, buildings and encampments. A simple pre-plan was made to always have food to offer, always treat the participants kindly and as equal with the researcher under all circumstances, including when they were suspected of using illicit drugs. Sharing food is closely related to sharing photographs, cameras and stories, which was done at each meeting. The recurring meetings and the acts of mutual sharing led to the development trust and created incrementally stronger social bonds between the researcher and collaborators over time. The researcher was always respectful of the participants' identities and experiences, especially when invited in to visit participant social networks. The neighborhood meetings and visits to their communities were often positive social experiences and served to deepen the understanding and knowledge of the researcher to the lives of each participant and the difficulties they faced daily.

Additional ethical challenges to the research project were presented by friends of the participants who would ask the researcher if they too, could join the photographic investigation. These people were always treated kindly and were informed that enrollment had unfortunately been completed. These people were also part of the community and although they infringed on the anonymity of some participants, they also informed a deeper understanding of the relationships that long-term opioid users had in the communities in which they lived. Each introduction to a friend or acquaintance informed the researcher about the participants' lives and each experience visiting their neighborhoods allowed the researcher to better understand their communities and the circumstances that informed their long-term opioid use.

Another example of an ethical challenge occurred during an interaction with a participant while in the researcher's car. On a very cold and rainy day in winter, a participant had no way to get home from his clinic in the early evening. After meeting for an interview, the researcher gave him a ride home, but was pulled

over by the New Haven police for expired registration on the researcher's car. The participant, having had his own personal experiences with the New Haven police, grew nervous in the passenger seat as the researcher explained to the officer that the researcher unfortunately, had no registration nor identification with him as he just returned from Liverpool on a flight the evening prior.

The police officer was polite, and the researcher used his cell phone as a form of identification that satisfied the officer and the researcher was allowed to leave with only a verbal warning to carry ID and automobile registration while driving a car in CT. On continuing the trip home, the participant explained , with arms wildly waving in the air, that never had he experienced a New Haven officer treating a person with expired registration and an identification discrepancy, without punishment or bold mistreatment. The participant then began to explain his perspectives on law enforcement and revealed intimate details about his experiences with discrimination, intimidation, imprisonment and episodes of physical abuse by New Haven police. The experience of getting stopped by the police for an automobile registration infraction led to a deeper understanding of how the power dynamics between the participant and the police in New Haven developed over years. This deeper understanding by the researcher may not have been possible without the unpredictable event and preparing for the unexpected, while adhering to the appropriate cultural competencies to fit each individual.

The researcher had many other moments that resulted in unexpected ethical challenges, each requiring critical self-awareness and cultural proficiencies to make appropriate decisions while protecting the integrity of both the participants and the research project. Ethnography is admired for its ability to uncover the deep meaning of experiences and to utilize those unexpected experiences to learn about people, culture and their ecological environments.

6.4 Answering the Research Questions

1. What are the factors that contribute to long-term opioid use in Liverpool and New Haven, and how do individuals experience these factors in their daily lives?

The factors that contribute to long-term opioid use in Liverpool and New Haven are complex and stem from fundamentally different healthcare frameworks as described previously within this paper. While opioid dependence is ubiquitous regardless of location, the frameworks upon which opioid use and dependence are recognized and treated in each country are rooted in historically unique governmental policies, motivated by distinct historical circumstances and supported by divergent laws. These historical policies, as well as the changes in policies over the last 100 years, have pertained to the pharmaceutical use of opioids, the categorization of opioids among other addictive drugs, the legal distribution of opioids, guidelines for appropriate personal use, penalties to enforce violations of opioid distribution and criminalization of problematic opioid (mis)use. In both the UK and US, prescription and illicit opioid use has been well chronicled for over 100 years, providing countless opportunities for generations of policymakers to reimagine, redesign and reclassify laws and policies as opioid use expanded over decades.

What sets the UK and US apart are the healthcare systems under which each population exists. As opioid use and dependence are directly related to health, policies and regulations have evolved to meet the changing cultural and medical needs of generations of opioid users. While residents and legal visitors in the UK enjoy universal healthcare services provided through the NHS, residents in the US do not have a similar form of universal healthcare coverage. Healthcare coverage in the US, with some exceptions, is largely a for profit system offering a range of health services based on health plans chosen and paid for by the individual, the individual's employer or both.

While services for opioid dependent individuals in the UK may be imperfect, participants described the wide availability of OST and group talk therapy. UK participants described the long-term use of prescribed methadone over years and even decades, with some UK participants regretful of years spent using methadone without making positive steps toward an abstinence-based recovery from opioids. Third sector drug services have proliferated over the last decade as a way to provide cost-effective drug treatment services, austerity measures have forced deep cuts to expenditures in the face of rising healthcare costs. However imperfect, the *right to health* care in the UK includes the right to access drug treatment services both at home and while in prison.

This type of universal national healthcare is not provided to the citizens of the US. Healthcare institutions in the US, in nearly all instances, require patients to accept financial responsibility for services rendered. Healthcare systems provide discounts to network members and exclude those without in-network healthcare insurance policies, which increases costs and further alienates those without insurance policies, compelling a financial obligation to high fees or choosing to go without healthcare, depending on the patient's ability to afford or negotiate a plan to pay the health treatment costs.

The second factor implicated in the experience of long-term opioid dependence in the UK and US is the wide availability of prescription opioids in the US marketplace, created almost exclusively through the over-prescription of opioid-based pain medications by US prescribers. As described previously in this paper, prescriptions for opioids have served to ingratiate fee-based practitioners with fee-paying customers seeking remedies for pain, opioid dependence or both. Contented patients who are prescribed opioids are both more likely to maintain a consistent connection to a practitioner and recommend that practitioner to others, thus helping an unprincipled medical provider to grow and maintain a professional healthcare practice in an increasingly competitive and unethical US healthcare marketplace.

Published research identified that unused prescription opioids continue to be the most common method of introduction to opioid use and prescription opioids have been widely implicated in the development of new onset opioid dependence behaviors. While evidence suggests this issue exists in the UK, the NHS network of GP practitioners largely prevents the over-distribution of opioid pain medications and largely prevents doctor shopping within the healthcare sector for an opioid prescriber, unlike in the US.

The third factor that contributed to long-term opioid use among the participants was entrenched economic disadvantage, which was identified in both New Haven and Liverpool and was described as a combination of several structural factors including: poverty, substandard living conditions, high unemployment due to lack of job opportunities and social distress.

Over the last 50 years, both Liverpool and New Haven have seen rises in deindustrialization, cuts to programs that maintain the social safety net and growth in rates of unstable housing. As a result of these negative changes, economic and social distress have increased and compounded problems associated with racism, physical and mental health needs and access to healthcare.

Economically disadvantaged communities have been found to have higher rates of drug use including opioids, higher rates of overdose, increased rates of crime, greater participation in the illicit drug economy and increased rates of incarceration among racial and ethnic minorities. Both Liverpool and New Haven have experienced a positive association between these socioeconomic factors and a rise in drug dependency problems.

These structural problems and health disparities serve as obstacles to easy solutions and increase the stressors of people who live in economically disadvantaged communities. These obstacles have been found to contribute to physical and mental health problems while also hindering access to healthcare, creating a synergistic effect that further alienates the poor and those with long-term drug use problems and have resulted in shorter life

expectancies, increased rates of ACE and adult traumas and increased rates of imprisonment among these economically disadvantaged groups.

These three issues were experienced by the participants and affected them in different ways. For those from Liverpool, the introduction to opioid use was not through the use of prescription opioids, but through the use of smokable and injectable illicit heroin. As opioid dependence gained control of users' lives, practitioners used cost-effective treatments to curtail problematic opioid use and decrease community related crime by prescribing methadone to illicit opioid users in the UK. Liverpool participants described how the rapid increase in illicit opioid use in the 1980s and 1990s prompted criminal behaviors and eventually led to increased rates of imprisonment. Often after several cycles of returning to jail or prison, some participants chose to accept a script for daily methadone, unaware that the methadone script would likely serve as a stand-alone treatment for opioid dependence lasting years or even decades. The socioeconomic factors listed previously were experienced by the Liverpool participants and wide agreement about their complicity in the local opioid epidemic was reported.

For participants in New Haven, these same socioeconomic factors played an important role in creating the conditions that allowed for opioid consumption to flourish. Availability of illicit opioids increased as economic opportunities and jobs decreased. The proliferation of prescription opioids allowed for inconspicuous consumption and easy resale during the early days of the rising opioid epidemic in the northeastern US. As opioid use and dependence grew stronger over time, the needs of users to increase their dosages eventually necessitated a switch from prescription pills to injectable heroin due to its lower cost and wide availability. As stated by many of the New Haven participants, several different types of illicit prescription medications were readily available for sale in the local community because selling prescription opioid medications has been profitable in local disadvantaged communities and a socially accepted method of generating income when other career opportunities have diminished.

2. What services and treatments have been provided to people who use opioids and what services and treatments did individuals want to participate in to improve health and reduce opioid use?

Participants explained how treatments and services may or may not have had a beneficial effect on changing drug use behaviors, but availability of those services needed to remain for those willing to participate. Participants overwhelmingly wanted options and opportunities to access health services when they personally perceived a need for a drug use intervention. Available services for participants in Liverpool and New Haven were similar in that both communities believed the best plan for recovery from opioids included opportunities for detoxification, rehabilitation, OST and group therapy.

Only one participant reported zero experiences with clinic-based detoxification, rehabilitation, OST or group therapy and ironically, in the opinion of the researcher, that participant was using opioids during data collection. All other participants believed broad access to drug treatment services and OST was the only way to decrease opioid use and maintain a steady pathway to recovery from drug dependency.

In terms of frequency, one UK participant said he had gone into either a detoxification unit or a rehabilitation unit at least 50 times, while others described dozens of detoxification experiences. UK participants verbalized some dissatisfaction with the distances they were sent from Liverpool for detoxification treatment and the short length of stay allowed in certain drug rehabilitation institutions, but overall, the UK participants reiterated the fact that an individual may need to attend detoxification and/or rehabilitation several times before a person can take responsibility for an OST regimen and maintain consistent participation in group therapy. All UK participants had close connections and positive things to say about group therapy, particularly involvement with NA and AA, which were found to be beneficial and widely available in Liverpool.

The New Haven cohort described attending detoxification and rehabilitation treatments mostly as a result of a court order. US veteran participants had experiences with elective detoxification and rehabilitation treatment programs provided by the VA, but New Haven non-veterans shared no experiences of drug treatment without arrest and imprisonment due to the unaffordability of detoxification and rehabilitation programs in CT. Court mandated detoxification and rehabilitation programs in CT are paid by the state and individuals who choose an opioid treatment program over prison do not immediately get a reduced prison sentence. Court mandated opioid treatment may last months and the New Haven participants had mixed opinions about being mandated to drug treatment based on the quality and conditions within the drug treatment institution. Some New Haven participants described getting treatment a few times, but more often detoxification was a forced consequence of imprisonment for drug-related crimes.

Universally, participants expressed the belief that individuals are unique and need different treatments and services. Some participants described *windows of opportunity*, moments of open-mindedness that coincided with a personal decision to seek help with drug dependence, because as participants said, *"you cannot force a person to quit using opioids who does not want to quit using opioids."*

3. What strategies for the reduction of opioid use among older people can be shared inter-culturally between Liverpool and New Haven to decrease rates of long-term opioid use?

Findings suggest that long-term opioid dependence, problematic opioid use and opioid overdoses affect more people in the US than in the UK for reasons stated previously in this paper. While rates of opioid use continue to increase in the US, rates of opioid use are flat, or even slightly decreasing in the UK, in part due to the tight distribution of prescription opioids in the UK, the wide social acceptance of OST and the availability of OST services throughout the UK. The single greatest strategy to decrease opioid use in the US, would be to change the healthcare model to resemble a universal healthcare system

similar to the NHS model and prevent opportunities to doctor shop for opioids from multiple prescribers in multiple cities and states. Limiting the widespread availability of unused prescription opioids would significantly reduce the opportunities to initiate new opioid consumption in the US.

Secondly, in comparison to the UK, the US has a very low rate of buprenorphine and methadone use for the treatment of opioid dependence. These medications were found to carry significant stigma for both clinics and patients in New Haven. US federal drug policy continues to maintain an abstinence-based approach to drug treatments, in large part, because drug use continues to be associated with the outdated argument that drug dependency is a moral failure of the individual. Federal drug policies continue to prevent or discourage the broad use of methadone for extended periods due to the risks of misuse and diversion. The use of buprenorphine, while widely used in the UK, continues to require practitioners and prescribers to apply for a special waiver and seek a specialized certification to be approved to prescribe buprenorphine and methadone to opioid dependent individuals. US prescribers are reluctant to apply for these certifications because opioid dependent people are stigmatized, discriminated against and un-welcome in the waiting rooms of typical primary care practices. Prescribers are reluctant to expand care to drug users who will visit primary care waiting rooms and sit alongside the institution's non-drug using clientele. For-profit healthcare systems allows practitioners to choose for themselves which populations they would like to serve, rather than the assignment of an individual to a particular GP practice as is done in the UK. Systemic and institutionalized discrimination toward drug users exists within the US healthcare model and within waiting rooms partially filled with drug users. This new waiting room culture may negatively affect patient satisfaction rates in clinics and potentially impact the profitability of traditional healthcare offices as patients may choose to move to a different clinical practice that does not cater to people who require opioid maintenance regimens and may be living on the streets.

Lastly, expanding the use and acceptance of AA & NA in the US would provide an additional opportunity for opioid users to participate in group therapy as a

way to maintain recovery and sobriety and increase community connections, which are proven strategies for improving the health of people with problematic opioid use issues. New Haven had few opportunities for local participation in well-organized AA and NA meetings. Liverpool appeared to have significantly more opportunities for group therapy and talk therapy meetings than New Haven with long-established AA & NA groups serving the needs of the Liverpool community. Among the New Haven participants, only veteran participants with connections to the VA hospital were regularly attending AA & NA meetings. The veterans verbalized satisfaction with group therapy meetings which were located on the VA campus in West Haven and run by VA hospital employees.

4. What obstacles are implicated in fostering the continued rates of problematic opioid use in each location, and how do those structural factors differ between Liverpool and New Haven?

According to the research findings in Liverpool, long-term methadone use was mentioned frequently as a stand-alone treatment for long-term opioid dependence. Many Liverpool participants indicated that abstinence-based recovery often required an individual to motivate themselves to take sole responsibility for getting off methadone, as prescribers were content with long-term methadone script use as the sole remedy for drug dependency. OST was a widely accepted treatment in the UK and was found to be an effective and cost-efficient treatment for opioid dependence, while in the US, only a small percentage of those who would benefit from OST actually received OST treatment. This US deficit in OST use was due in large part, to a lack of US providers willing to treat PWUD in the primary healthcare setting. As stated previously, systemic discrimination toward drug users was found to exist within the US healthcare model and continued to be an obstacle in the quest to reduce problematic opioid use. Additionally, the lack of widespread OST is complicated by the lack of OST in US jails and prisons. MOUD in US jails and prisons has been identified by the participants as a major factor contributing to continued opioid use and a treatment modality that participants wanted for themselves and for others with OUD in jail and prison in the US.

According to the research findings, some non-veteran New Haven participants continued to lack basic necessities for living, including safe and permanent housing, a means of financial stability and consistent health care services. This was not the same situation for the participants from Liverpool and the participant veterans in New Haven with access to VA healthcare. Broad homelessness and specifically rough sleeping continued to impede any progress toward physical, psychological, or interpersonal health improvements and increased the risks for polydrug use, criminal behavior and hopelessness, all of which were common experiences for those participants without consistent shelter options.

The greatest obstacle facing long-term opioid dependent individuals in the US was entrenched discriminatory disadvantage: the lack of support systems for housing and homelessness, unaddressed physical and mental health needs, and all forms of stigma and against PWUD. These obstacles were the result of deep rooted and socially accepted institutional discrimination and will not change without fundamental shifts in how American culture accepts responsibility for all people, including PWUD. A formal policy change to provide all citizens of the US, the *right to health* and health care services would serve to create a more equitable environment for PWUD, minorities, the disabled, people with housing problems and countless other marginalized groups. These proposed changes would require federal policy makers to fundamentally restructure how healthcare is funded and accessed by over three-hundred eight million Americans.

Opioid recovery, in all its manifestations, is a continuum that begins with actions and behaviors toward the reduction of opioid use with the goal of attaining improvements in physical, relational, emotional and spiritual health. Recovery requires an individual to accept and assert themselves through positive actions, to mobilize personal strengths and participate in incremental transformative steps to reintegrate back into their community. Recovery requires assistance and the participants from Liverpool described experiences within the Liverpool recovery community that did not widely exist in New Haven outside the VA. The *right to health* and healthcare services would benefit this

population in the US by decreasing opioid-related overdoses and deaths, decreasing institutionalized stigma and increasing cultural acceptance of PWUD as equal members of society.

6.5 The Ethics of a Visual Research Investigation Among PWUD

Representation in qualitative visual research carries unique responsibilities, especially in single researcher investigations. Accurate representation of research participants depends on an adherence to ethical standards, IRB protections and researcher integrity. Of equal importance is researcher reflexivity to understand, communicate and contextualize unique life experiences and the factors that influence participant behaviors, motivations and attitudes while adjusting researcher priorities and making small changes to benefit the participants and the authenticity of their stories.

Representation by a single researcher is not uncommon in ethnographic investigations, however this issue may be recognized as a potential weakness in this investigation. While the researcher was first to identify this issue, the choice to use a MIEF was developed and implemented to: *(a)* allow the researcher to experience and understand the ecological environment of each participant-photographer without directly influencing, directing or planning topics for discussion; *(b)* provide the researcher with the full experience of collecting every participant narrative to make educated and authentic decisions about the interpretation of deeper meanings, intentions and motivating factors from the participants' own words; *(c)* provide the researcher with the full experience of collecting and discussing every participant photograph to make educated and authentic decisions about the interpretation of deeper meanings, intentions and motivating factors from the participants' own photographs and *(d)* allow a single researcher to absorb all these experiences to make ethical decisions about data integrity, data authenticity and which participant-related issues to include or exclude in the analytical processes.

The MIEF required the researcher to accept *interpretive authority* and to be solely responsible for how the participants were represented within the study. This issue of researcher responsibility was critical and existed between the boundaries of *naturalistic enquiry* and *interactionalism*, the conditions caused through the relationship between participant and researcher and the effects of inherent power dynamics that existed within each individual collaborative partnership.

Researchers must constantly make choices and decisions about data. Representation requires researchers to work systematically and reflexively to present findings in an authentic and accurate way. Authenticity is assessed by the researcher and comes with great responsibility. In this study, *engagement* served to place the researcher in a unique position from which to process the experiences, interactions and narratives through the use of knowledge derived directly from every researcher-participant interaction.

The researcher recognized the responsibility to data integrity and ethical decision-making. The researcher recognized the importance of not only collecting, transcribing and categorizing the data, but the need to bring authentic and honest experiences out from behind the words of the participants. This responsibility was the reason member-checking was used in stage three: recontextualization. Member-checking necessitated transparency in how the findings were developed and provided increased trustworthiness of the findings. Researchers should be critically aware of the importance of protecting the meaning and intentions of participants while striving to prevent the exclusion, erasure or dilution of participant identities. The use of MIEF effectively protected the unique participant identities while it allowed for a single researcher to uncover meaningful and unique findings and disseminate those findings to stakeholders, policymakers and the wider world through engagement.

6.6 Chapter Summary

There are several interdependent and overlapping issues that contributed to participants' lived experiences and the problems they faced with long-term opioid use. Limited access to healthcare and drug treatment services, ACE, adult traumas, broad homelessness, broken relationships, imprisonment, poly-substance abuse, social hardship and violence were all implicated by the participants as contributing factors to opioid use. Each of the problematic issues was identified through personal conversations with the researcher and revealed the unique complexity of each participant's position within their ecological environment.

This chapter provided a discussion of why the use of an ethnographic approach benefitted the research study, why a researcher-centered approach benefitted the visual and thematic analyses, and how being well prepared, reflexive and accommodating were necessary skills to bring to a research collaboration with PWUD.

This chapter also explained how the research methods and design served to answer the four research questions. Each of the 4 research questions were answered in detail and each answer examined the nuances and similarities between the experiences of people in Liverpool and New Haven.

Lastly, this chapter provided a short discussion of the necessity for a single researcher to accept interpretive authority through the implementation of a novel modified research framework to ethically and accurately articulate the experiences, circumstances, perspectives and needs of older long-term opioid users who participated in this ethnographic investigation.

Chapter 7: Discussion

"If we are to achieve a richer culture, rich in contrasting values, we must recognize the whole gamut of human potentialities, and so weave a less arbitrary social fabric, one in which each diverse gift will find a fitting place." (Margret Mead)

7.1 Introduction

From the beginning of this investigation, a research foundation was constructed upon *epistemic relativism*, the position that knowledge is valid relative to its specific contexts, societies, cultures and relationships. This chapter discusses the practical understandings from the research on older opioid users in Liverpool and New Haven and uses participant quotes to support and compare the findings to the literature introduced in Chapter Two. The research findings were found to encompass several factors implicated in the exacerbation of opioid dependence, opioid related illness and opioid related death. This discussion compares the institutional, cultural, economic and political differences between UK and US drug practices and the effects those differences have on the health and lives of older people who use opioids. This discussion also suggests ways to improve the health of older drug dependent people through the recognition and elimination of the *stigma of addiction*, the expansion of OST programs for people in prison, increased access to US healthcare services through Medicaid and the Affordable Care Act and acceptance of the fact that opioid dependence is a treatable chronic disease and is neither a moral failing nor the result of a lack of personal willpower.

7.2 Stigma

The *stigma of addiction*, the act of being negatively labeled, stereotyped or discriminated against due to chronic drug or alcohol use, drug dependence or SUD was an overarching issue that the participants directly connected to the critical problems of homelessness, housing instability, imprisonment, law enforcement interactions, employment and personal relationships.

Participants described recurring stigmatizing interactions with community members, healthcare workers, law enforcement officials, shelter staff members, bus drivers, local business owners, family members and elected politicians. Previous published research has found that the stigma surrounding opioid dependence is persistent, pervasive and rooted in long-held cultural beliefs that follow two main theories; that opioid dependence is the result of a lack of personal willpower to maintain sobriety within a community, and/or that opioid dependence is the result of a personal moral failing. Both labels serve to denigrate and negatively identify drug users as less than others who do not use drugs (Nordenfelt, 2010; Harding, 1986). Participant drug users, specifically black participants from New Haven, experienced discrimination and racism through persistent social segregation, social and institutional discounting, inattention to personal needs, verbal cues and micro-aggressions by acquaintances, strangers, and people with power in healthcare, housing and social services.

In 1997, Alan Leshner, who served as the Director of the National Institute on Drug Abuse (NIDA) from 1994-2001, wrote,

> *"One major barrier to closing the gap between scientific and public understanding is the tremendous stigma attached to being a drug user or, worse, an addict. The most beneficent public view of drug addicts is as victims of their societal situation. However, the more common view is that drug addicts are weak or bad people, unwilling to lead moral lives and to control their behavior and gratifications. […] The gulf in implications between the 'bad person' view and the 'chronic illness sufferer' view is tremendous. As just one example, there are many people who believe that addicted individuals do not even deserve treatment. This stigma, and the underlying moralistic tone, is a significant overlay on all decisions that relate to drug use and drug users" (p.45).*

Leshner accurately characterized the long-standing negative opinion of drug dependent people with this description and in doing so, confirmed the

existence of the deep-rooted *stigma of addiction* that is pervasive in personal interactions within institutions, law enforcement, the prison industrial complex, health care and interpersonal relationships.

As supported by Serre (2018) and Green (2014) in the literature review, the *stigma of addiction* was found to discourage or limit the willingness of individuals with opioid problems and their adult caregivers to seek treatment, reduced the willingness of healthcare providers in non-specialty settings to screen for and address substance abuse problems, and reduced the willingness of policymakers to allocate resources to mental health, which were issues identified in the experiences of these participants.

A quote from participant RW embodied the difficulties homeless drug users experience when they have no options and are affected by the *stigma of addiction.*

> *"Well, the services [in New Haven] they have for people in my predicament are tough. I've had some bad experiences in the past, dealing with the shelter system. That's why I don't really like dealing with them, with the staff. Staff members act like they're in charge. Just different people and different personalities so that's why for the last few years I have been staying with friends, but it is a catch 22. Because if you don't go through the shelters, and they want you to go through their little system before they even move you onto the next step. Before they really help you. I guess they figure that if you're sleeping on somebody's couch you are not homeless. That's the way they look at it." (RW, USA)*

A rare interview-based research study among older opioid users found that there were several factors that contributed to stigma among older PWUD and that the experience of multiple, concurrent stigmas can compound physical and mental health problems (Conner, 2008). Eight distinct stigmas were identified in the study: (a) drug addiction stigma, (b) the stigma of older age, (c) the stigma of taking psychotropic medications, (d) the stigma of depression,

(e) the stigma of receiving MMT, (f) the stigma of poverty, (g) the stigma of race, and (h) the stigma of HIV (Conner, 2008). The findings of this present study supported the existence of all eight distinct stigmas found in the previous research study.

While the *stigma of addiction* was found to be a central factor described in both previous studies and within this current research, the combined impact of the stigmas of addiction, ageing, depression and taking medications for drug dependency were common and impactful. These stigmatizing interactions occurred primarily with friends and family members who did not support their drug use behaviors, and from health care professionals, treatment counselors, and staff members at treatment facilities, which correspond with previous research findings (Melin, 2017). The stigmatizing experiences of the participants in this study were strikingly varied in their descriptions of discrimination and the damage those encounters had on daily social and institutional interactions.

A quote from MR illustrated how racism and the *stigma of addiction* compounded problems for homeless black drug users in New Haven.

> *"I don't really care if it is a shitty shelter, your ass isn't sleeping outside for the night. But people (PWUD) aren't ready to go home, so I wonder what they're thinking about. When you're out here on a cold bench, people walking past you, you don't know what evil they have on their mind. But the worst is the police riding by will wake your ass up and toss you around. It is then that you need to make the choice of life, would I rather go through this, or would I rather be in jail? Being incarcerated until springtime just to get someplace warm to stay? And something to eat? It's just monotony over and over again and as soon as somebody moves on another person just moves in. I don't care how old you are […] you become a product of what you were brought up in."* (MR, USA)

Previous findings from a study by Rosen (2011a) found evidence of the negative experiences of combined marginalization and stigmatization among a cohort of older black men who accessed a single methadone clinic in the US. Both the respondents from Rosen (2011a) and Conner (2008), described the stigma experienced from judgements regarding injection drug use (IDU), receiving MMT and their older age as the most damaging types of stigmatizing experiences. In both previous studies, the experience of multiple and concurrent stigmas caused respondents to have a continual and chronic fear of negative judgements from others. These multiple and overlapping stigmas were identified in the previous studies as significant barriers to seeking treatment, remaining in treatment and as a primary cause for leaving treatment (Allen, 2019; Rosen, 2011b; Conner, 2008).

A quote from a female participant from Liverpool exemplified how repeated discrimination and failure to recognize the individual needs of drug users causes PWUD to withdraw and disconnect from outreach services, which was considered by AA as the opposite of acceptance.

> *"These so-called drug addicts, these so-called low-lifes are interested in what's going on. All they need is a little bit of direction and help. That's all they need. I have a good family. Some of these young lads don't. I have a dad and I'm the only mess up in my family. All of my family are dead normal. I don't know why I ended up the way I did. Issues and things that happen as a kid, I suppose. I tried to escape reality and then you realize when you're 40 it wasn't about escaping reality it was about being accepted. All them years that's all you wanted. Accept me for what I am. Yes, I have a little bit of issues, but accept me for me. Because you know it's a hard road to travel when you're on drugs. Because they label you anyway and then they discriminate because of the drugs, and you never feel good enough no matter what." (AA, UK)*

While the *stigma of addiction* was found to be directly connected to the experiences of the participants in this current study, racism was also found to complicate many interactions between white drug users, white people of authority and the black and brown participants. 12 participants in the US cohort acknowledged the experience of being treated unfairly and interactions where those in positions of authority discriminated against them based on being a person of color. These racist interactions were described as commonly occurring and ranged from micro-aggressions, defined as "brief and commonplace verbal, behavioral, or environmental indignities, whether intentional or unintentional, that communicate hostile, derogatory, or negative racial slights and insults toward people of color" (Sue, 2007, p.274) to overt law enforcement and judicial actions such as police stops, searches, arrests, use of force, wrongful conviction and overly harsh judicial sentences. Racism was also a significant finding in Rosen (2011a), described as direct and indirect indignities directed toward the older black men who lived continuously in the same city for several decades while using illicit opioids.

Participant MR believed that actions of local police were informed by the rhetoric of the right-wing President and that the current culture of racism was increasingly tolerant of the mistreatment of black drug users in New Haven, which may lead to more illicit drug use.

> *"You see what's happening with the police and Donald Trump, talking about, let's make America how it used to be. What was it (America)? It is prejudiced, soup lines, prejudiced, no jobs, prejudiced, prejudiced, prejudiced. And they (police) say I can shoot your ass if I want to because I'm white, or you better shine my shoes, nigger. And you better not be in this neighborhood after the sun goes down. There's just all kinds of mess and a lot of reasons that make people use drugs." (MR)*

The findings from the present study along with Rosen (2011a) and Conner (2008) revealed that although stigma in and of itself, may not have been directly responsible for the all the negative conditions of the participants lives

and their drug dependency, the experience of the *stigma of addiction* was found to be a major factor in the lives of older, drug dependent people and could be implicated as the single greatest overarching problem which prevented older PWUD from accessing healthcare, safe and adequate housing, drug treatment services and employment. As identified in the literature review, institutionalized stigmatization, discrimination and racism protect and maintain historical and outdated systemic inequities which instill implicit biases that favor *in-groups* and discriminate against *out-groups*, such as PWUD and in particular, the participants of color in this research study (Balko, 2020; Allen, 2019).

7.2.1 How Rough Sleeping, Broken Relationships and Trauma Experiences are Associated with Opioid Dependency

As revealed in this study and other published research, older people with substance use problems need help with more than active drug use. Many older people with drug dependency problems need help with physical and mental health issues, safe housing and interpersonal relationships (Melin, 2017; Beynon, 2009). Many older people with opioid dependence issues in this study and others experienced multiple episodes of imprisonment within the criminal justice system which often solidified lasting social stigmatization by friends, family, community members, healthcare workers, employers and institutions (Melin, 2017; Tyler, 2017). As described by the participants of this study and others, arrest and imprisonment for drug dependency related crimes often resulted in lost opportunities to participate in family relationships, difficulty in gaining employment and problems with maintaining safe and affordable housing (Mayock, 2021; Melin, 2017; Tyler, 2017). Participants in this study confirmed previous research findings that social isolation from friends and family promoted lasting depression and often contributed to long-term problematic drug use (Neale, 2016; Rosen, 2011a; Beynon, 2009).

Participant JO described how hopelessness and depression develop from the cycle of reimprisonment and how care, assistance and services are necessary to prevent the death of older drug users.

> *"If you're 50, you like got no get-up-and-go in you. If you've got no money you're going to go out and rob somebody. Even though you're old, if you rob the wrong person you're probably gonna get killed for it. But if you've got no money when you're 50 and you're homeless and you're skint, you will die. You will die at the end of the day. And that's the last resort because you can't look after yourself. …Most people now who are homeless who go to jail, they go just for the meals and the roof. They will sacrifice a couple of nights just to get fed. Crime leads to jail anyway, so you're going to jail if you commit a crime. It's all intertwined, isn't it?" (JO, UK)*

This research study confirmed previous results that long-term problematic opioid use dismantles an individual's connections to family, relationships, and health which without assistance can lead to homelessness, risk for opioid overdose and reimprisonment; a cycle that is very difficult to stop and very difficult to control without support (Neale, 2016; Rosen, 2011a). A quote from a female participant from New Haven illustrated the fragility of the connection between mother and child when drug dependence is a factor.

> "*I left my daughter there with my mom and I kept saying I'll be back, but time went by, and I couldn't get back. I wanted to, but I just couldn't do it. …So, I just kept running the streets for years after that. I became homeless. Prostitution was big on my list. I just got very tired. I was almost killed at gunpoint and beatings and stuff, like that happens on the streets." (LC, USA)*

In discussing the association between rough sleeping and opioid dependency, a US participant explained, "*you don't become homeless when you run out of money, you become homeless when you run out of relationships." (RW, USA).* This statement and similar descriptions of the experience of homelessness

and rough sleeping characterized the seriousness of having no options for housing, no connections to the stability of family or friends, no access to money and a lack of protection from street crime and law enforcement actions.

Similar findings from published research have identified a relationship between homelessness and drug dependency. Neale (2001) described how the relationship between homelessness and drug dependency is complex and can be related to the experiences of childhood abuse, family breakdown, and problematic childhood behaviors. Neale (2001) detailed how PWUD may likely become homeless due to two common and interrelated factors: relationship breakdown and discharge from prison, which leave an individual without options and increase the risk for drug overdose and a return to criminal behavior.

CE was a woman from Liverpool who conveyed the difficulty of broken family relationships and the impact broken relationships have on polysubstance use, homelessness and being an older PWUD.

> *“For somebody like me I had never worked, I left school at 16. I was a heroin addict just after my 16th birthday and I spent 28 years in active opiate addiction. It was only by the grace of God that someone helped me find a way out, but my brother is still in opiate addiction, and he has just turned 50. We grew up together, there's only 11 months between us, so to see my brother at 50, he has the same sort of mindset as people who live in the city, you know he is skint (financially broke). He has nothing really. The people who are living like that, they don't have any opportunities. They have no resources. They feel like they don't have any skill set to fall back on. And a lot of times by the time you get to 50 and you've been on opiates all them years, you feel like you have burnt all your bridges with people because you have absolutely tapped people to death for money. You've lied. You've stolen. You've deceived people. So, I think it is a very sad, hopeless place to be.” (CE, UK)*

In discussing the issue of broken relationships, the findings from Melin (2017) established how opioid dependence was found to cause separations between people with drug use behaviors and their non-drug using friends and family. Melin (2017) found that over time, the requirements of opioid dependence and the need to procure opioids became more important than their prior relationships and often progressed to the betrayal of loved ones and the dismantling of previous intimate partner relationships. Participants from both Liverpool and New Haven described the same realities of opioid dependency in their own lives and suggested that loved ones could not prevent their impulsive behaviors to seek out more drugs, nor stop them from participating in the criminal behaviors associated with financing their drug dependence.

In comparison, Melin (2017) also confirmed the results of the present study by noting that drug seeking criminal behavior caused family, friends and people in the community to fear them and create distance between themselves and the person using drugs. The fear of individuals exhibiting drug use behaviors was found to lead to ostracization, anger and increased anxiety, which in turn heightened feelings of guilt and shame for the person using drugs and increased risk for drug overdose. Additionally, previous research identified that the transition into criminal behavior replaced relationships among loved ones with new associations among criminals, the need to adopt a tougher persona and engagement in increasingly violent activities to procure money for drugs (Melin, 2017). These findings were consistent with many participants from Liverpool and New Haven who had experience with committing violent crimes to finance their drug dependency as described by GP in the following quote.

> *“When you've got a heroin habit and you have to go out and you're committing crimes, it's about getting the money. Sometimes you can't get the money, so you find objects to sell. Then you've got to find somebody to buy them off your hands for a decent enough price. You can be in the shop shoplifting all day or whatever your crime is, but you're going to be at it all day. It's a ca*
> *reer now, do you know what I mean? (GP, UK)*

ACE and adult traumas were described by the participants from Liverpool and New Haven as significant complex factors that contributed to the personal experiences of homelessness, broken relationships, physical and mental health problems, drug dependency, criminal behavior and imprisonment. While the range of ACE reported by the participants included physical, sexual and psychological abuse, the frequency, severity and individual impacts of the experiences were broad and varied. For some, particularly the female participants, the experiences of sexual assaults prompted a conflict between a desire to escape the abuser when possible, while having no money, no place to go and no one to turn to for help. The combination of victimization and social isolation increased anxiety and further motivated additional polydrug and alcohol use. For victims of multiple traumas, the lack of options for social assistance and safe housing promoted drug and alcohol abuse as a means to forget the pain and suffering caused by these experiences, which further contributed to the risk for drug overdose, physical and mental harm, participation in crime and potential imprisonment.

Previous published research from Stein (2017) supported the findings from this study by establishing an association between higher ACE scores and the initiation of opioid use, injection drug use (IDU) and risk for overdose due to intersecting biological and environmental influences. These biological (genetic heritability, parental modeling behaviors) and environmental (abuse, neglect, poverty, parental criminal justice involvement) factors were found to drain critical personal resources, disrupt social learning, and inhibit the acquisition of skills in children, which in turn promoted the use of opioids and other drugs as a remedy to the pain and suffering of multifaceted childhood and young adult traumas (Melin, 2017). A broad range of intersecting biological and environmental influences related to ACE and adult traumas were identified and described by all the participants from Liverpool and New Haven.

Previous published research also associated ACE and drug dependency with originating from the use of opioids as a means of escape from the difficult experiences of childhood and from reality (Melin, 2017). Above average ACE scores have been associated with smoking initiation, alcohol abuse, illicit drug

use, psychiatric problems, psychosis and suicidality (Stein, 2017). While ACE surveys were not distributed or quantified for the participants in the current study, there was found to be an association between their traumatic experiences of childhood and adulthood and their long-term involvement with alcohol and polysubstance misuse.

7.2.2 Prison Health in the US Should Resemble Prison Health in the UK

Cyclical arrest and the re-imprisonment of opioid dependent people was described by participants in both Liverpool and New Haven as a significant problem that had lasting effects on an individual's ability to participate in the community, enter the job market, rebuild relationships and secure safe and affordable housing. Cyclical arrest and re-imprisonment were described by participants in New Haven as heavy-handed tools of law enforcement and the criminal justice system, used to force polysubstance detoxification on drug users, in lieu of the availability of scarce and costly drug treatment services.

As identified in the literature review, the number of imprisoned individuals in the US with opioid dependency problems far exceeds the number of imprisoned individuals who receive opioid related treatment by a ratio of approximately 16:1, which spotlights both the neglect and mistreatment of imprisoned drug dependent people by policy makers and those in power (Malta, 2019). While rarely provided in Connecticut prisons, the use of OST for opioid dependent people has been found to reduce opioid related overdose and mortality, reduce opioid use and other risk-taking behaviors during and after imprisonment, and improve retention in drug dependency treatment programs after release from prison, a common practice on release from UK prisons (Malta, 2019; Marsden, 2017; Bennet, 2008; Mumola, 2006).

The participant experiences of being released from prison were strikingly different between Liverpool and New Haven. Participants from Liverpool explained how discharge from prison had improved over the last 25 years to include OST and referral to DRGs, while participants in New Haven were offered not offered similar protections and faced major obstacles to physical

and mental health, including enforcement of the Medicaid Inmate Exclusion Policy (MIEP). Since the inception of Medicaid in 1965, the MIEP has excluded and thus penalized a percentage of Medicaid enrollees by mandating the discontinuation of federal health insurance benefits for those convicted of crimes, which increases their risk for opioid relapse, overdose, homelessness and reimprisonment into the criminal justice system.

Participants in Liverpool with experience within the UK prison system expressed optimism with the slow evolution and expansion of prison drug services from the 1980s and 1990s when forced detoxification was used as was described by the New Haven participants. UK participants approved of the use of DDWs in some prisons and the distribution of OST to those with opioid use problems preparing for discharge. These new treatment strategies for imprisoned people with drug use problems in the UK reflect a significant change from the past experiences of stigmatizing physical violence from police in Merseyside and the stigmatizing mistreatment they experienced inside Cheapside Jail in Liverpool during the 1980s and early 1990s, as described by a participant.

> *"If you ask drug users who are my age, every one of them would know who Handlebars (jail staff) is. They will have had some experience with that mad cop or know some people who had experience with him. He was an evil individual. There's no other way to describe it, he was a vicious man. He was very cruel. Even when you looked at him you shitted. Because when I first ever met him, I had only known his name and he was feared. When I was like standing in front of him in Cheapside, I was terrified just on his reputation alone. He was an evil man."* (PJ, UK)

As noted in Chapter Two, the relationship between long-term opioid dependent people and recidivism has been well-established in the literature and in the findings of the present study (EMCDDA, 2012; UNODC,2009: Taxman, 2007). While it is estimated that approximately two-thirds of people in US correctional facilities have an OUD, yet only five percent receive OST,

US correctional institutions have a clear opportunity and moral obligation to adopt at minimum, policies to provide OST at the time of release from prison to reduce opioid overdoses, opioid related crimes and opioid related deaths among those returning home from US jails and prisons (Krawczyk, 2017; Morgan, 2013; NCASACU, 2010; Mumola, 2004).

As noted in Taxman (2007), drug-involved offenders in US prisons were found to have dependence rates that were four times greater than those of the general public which suggests that drug treatment services and correctional programs available to offenders were insufficient for the needs of this population. Recommendations for the improvement of both US correctional health care and for increased accessibility to community-based health care for drug-involved individuals, have been identified both in this study and in previously published literature. Recommendations have included the establishment of universal strategies for post release care, increased dependability and security in the transfer of medical records to GPs and improvements in external oversight and quality management throughout the US prison-industrial complex (Rich, 2014). These minimum recommendations are strongly supported by the principal researcher of this study as the first steps to reduce opioid related deaths among recently incarcerated PWUD.

It is the opinion of the principal researcher that US prison policies should adopt the same evolutionary changes as seen in UK prisons and provide OST, prison-based group therapy and referral services to all individuals released from US jails and prisons with substance use problems to combat the escalating rates of drug and alcohol dependency and overdose deaths.

7.3 The Difference Between the *Right to Health* in the UK and US.

The differences between the experiences of older people who use opioids in the UK and US are based on and linked to the fundamental differences in national positions to this question:

Is health care a human right?

The difference between UK and US health services for opioid dependent people was found to be directly related to how institutions and policy makers value and view their responsibilities to those without access to healthcare, are imprisoned or are homeless. The UK, with a population one-fifth the size of the US, appears to offer significantly more services to individuals with drug and alcohol dependency due to universal health care standards, a shared societal responsibility to care for everyone equally and recognition of the *right to health* for all citizens and legal visitors in the UK.

Long-term opioid dependence is a different experience in the UK than in the US, due to three compelling differences: *(a)* the ways egalitarian healthcare has been embraced and adopted by the citizens of the UK as an inalienable right; *(b)* the strong cultural connection between the continuity of satisfactory family health through generations and satisfaction with the services received from the NHS; and *(c)* the spillover effect; the ways in which the *right to health* has informed issues of equity and equality in public health, prison health, education, housing and drug treatment.

Over the last 70+ years since the inception of the NHS, the health system has seen countless changes and challenges driven by politics, political ideologies and society's changing perspectives of the what the NHS should be and do for the people of the UK (Henderson, 2014; Webster, 2002). Since its beginning in 1948, the NHS has established several metrics through which citizens have judged the success or failure of their healthcare system.

Over the last 70 years, the UK has experienced improvements in population health. Life expectancy rates have increased steadily increased while infant mortality rates have steadily decreased, both providing evidence of consistent improvements in care through the NHS (Taylor-Robinson, 2019). Public health policies implemented to decrease rates of smoking, improve rates of vaccination and screen for chronic diseases have served to improve the quality of life for individuals, families and society in both the UK and the US.

These improvements in population health have not arrived without costs. Structural, political and financial hurdles have historically posed challenges to improved health outcomes, however the NHS has remained instrumental in bringing the *right to health* to the people of the UK and creating an environment that embraces everyone as equal. These feelings of equality and equity in health have grown deep roots over several decades and have altered the way people view and access healthcare in the UK.

The NHS is not simply a healthcare system, but a way of life for the people it serves. People view the NHS as a part of who they believe themselves to be. The NHS is a lived experience and has become enmeshed in hearts and minds of UK citizens through a personal *relationship*, as described by a participant in the following quote.

> *"I think we're lucky to have it (NHS) and I don't want to lose it. I mean compared to other countries when you get sick, you're in trouble, even if you have insurance you're in trouble. Over here, we're very blessed. I've been on the phone to my friend and he's just got clean, and he can feel stuff now he's got, like decent pain. So, he comes down with these symptoms and now he's in a doctor's surgery waiting to be seen. There's nothing wrong with that is there? I have been over to Spain when one of my kids got sick and I spent the night in the hospital waiting to be seen and I was like wow that's the difference. I've got no criticism of the NHS. The only criticism of the NHS is that it might go. I think we're really blessed and I think it's really good. It's really professional. So for me to sit here and criticize the NHS, it*

would be wrong, everyone I know who has been ill has been well looked after." (PJ, UK)

Few people in 2022 can remember healthcare prior to the NHS, and few believe that removing the protections enshrined in the NHS would be best for its citizenry. The future outlook predicts economic difficulty for the NHS, but the *relationship* between the people of the UK and their health system is much deeper than the financial costs alone. The NHS has become an identity for citizens of the UK. The NHS remains an example of a social program that serves all people equitably and this achievement is widely admired throughout the world, including in the US. This was the unattainable health goal of Obamacare in 2009, which since that time has been stripped of many of its protections and recently escaped a challenge to fully nullify the Affordable Care Act (ACA) by the US Supreme Court in late 2020 (Ercia, 2021).

Egalitarianism is a political philosophy both observed within, and as a product of the NHS and as such, has had an overwhelming positive influence on other social programs in the UK. While the history of public housing, education and social care have roots that extend to a time far earlier than 1948, the ways in which the NHS supported the health of the population for over 70 years has informed other institutional relationships. The shared experience of the *right to health* has emboldened people to embrace a right to education, a right to housing and a right to social services. This does not mean that costs are to be ignored, but that health solutions should include everyone and should be the result of a collective agreement by the citizenry, based on equity and equality.

In comparing the NHS with the US health and US social care systems, there is a startling difference; the same free-market forces that have informed the US healthcare system have also slowly crept into social programs, prison health, the education system and political ideologies. America's free-market economy limits the extent to which a tax-paying individual must accept responsibility to cover the costs for US healthcare, education, housing and social services for all citizens. US free-market principles encourage competitiveness, cost-cutting, and greed. The hallmark of success in

competitive markets is the dominance of one product or business over another which translates to the healthcare industry. The US is significantly less willing to embrace an egalitarian philosophy to inform social, environmental, economic and educational programs for its citizenry due to the historical acceptance of free-market economics on both people and institutions. In extending these free-market principles to people and healthcare in the US, it becomes clear that egalitarian principles are anathema to free-market forces.

The New Haven participants faced a disproportionate number of obstacles to opioid treatment services, housing solutions and incarceration compared to those in Liverpool. The US veteran participants were clear in their assessments of non-veteran treatment opportunities in New Haven as limited and designed more for court-mandated requirements than for motivating opioid-dependent people toward recovery and rehabilitation. Non-veteran participants in New Haven described their experiences of a worse scenario; unstable housing, prolonged periods of rough sleeping and waiting lists for accommodations that continued for years. New Haven participants described the cycle of *arrest-imprisonment-release* as law enforcement's inability to implement any significant alternatives to arrest and abrupt detoxification from drugs in prison. New Haven participants described waiting lists for shelter beds, lack of access to mental health services and experiencing stigma, isolation and hopelessness.

All New Haven participants described personal experiences with the *stigma of addiction*, racism and discrimination by key health workers. These are the consequences of the progressive cultural acceptance in the US of inequality among Americans and unequal power dynamics that discriminate and stigmatize those without financial resources, who use drugs and who do not benefit from being white. Free-market forces are responsible for corrupting the spirit of a *we're-all-in-this-together mentality* by placing the importance of cost-cutting and profitability above the health of the American citizenry. Had the US followed the lead of the UK in 1948, we may now be looking at an entirely different and potentially much smaller, opioid epidemic in 2022.

7.4 Methodological Contributions of the Research Design

It has been said that a picture is worth a thousand words. What then, is the value of a picture *with* words?

Visual research endeavors have long perfected the use of photographs, video and film to answer social research questions in communities ranging from urban cities to isolated mountain regions and photographs have long been used in qualitative research to document people, culture, environments and events. Visual researchers have gone to great lengths to capture evidence of social phenomena and lived experiences within particular environments. This technological method of using photography to capture facts is not new. The process by which researchers use cameras as tools to study a topic of interest is not a uniquely novel approach to scientific inquiry.

However, in the field of drug use, specifically long-term opioid use among older people, published research has been quite limited in the field of addiction research. Qualitative investigations within drug using populations are fraught with challenges; drug users remain a hidden and vulnerable population, which makes ethical social research difficult if not impossible (Rhodes, 2006). Prior research to understand the life experiences and health needs of drug users have been documented in published literature for years, but rarely has a visual methodology been used to evaluate older people who use opioids and their lived experiences within their environments (Rhodes, 2006). Nearly all the published literature pertaining to the personal experiences of older, long-term drug users has been done either retrospectively, by meta-analysis or through face-to-face interviews. The author is aware of only one previously published, visual research project by Rosen (2011a), which distributed cameras among older people who used drugs; a study that used the Photovoice methodology among ten older African American men to learn their service needs, barriers to, and supports for abstinence from drugs. The findings successfully revealed details about the participants' service needs as they pertained to continued sobriety, identified barriers and supports, had a zero-attrition rate and ended with enthusiastic participants wishing to extend the project further.

While this author had experience with the successful implementation of a traditional Photovoice methodology to investigate housing and health needs among economically disadvantaged people in Haiti, the Photovoice methodology was found to keep the principal researcher outside the decision-making process (McRiley, 2012). The Photovoice methodology empowered the participants who spoke Creole, but no English, to lead and make decisions about all facets of the research study. Photovoice was not designed to provide researcher-led analysis, an important distinction between the author's prior experience and the goals of this current ethnographic visual research project.

The Modified Interpretive Engagement Framework (MIEF) provided a systematic approach to evaluate the deep meaning of participant-generated photographs, allowed participants full autonomy over the subjects photographed and the narrative descriptions of their images, provided the ability for participants to share their own experiences, work independently, avoid peer-criticism and focus specifically on capturing photographs that explained their life experiences as older PWUD. The 3-stage MIEF allowed the researcher to play an equal part in the development of research findings without diminishing the role and responsibilities of the participants. Stage one was a participant-led analysis, stage two was a researcher-led analysis and stage three was participant and researcher led analysis. Independent participant-researcher meetings allowed ethnographic research to occur in the participants' neighborhoods, communities and homes, which brought greater detail and understanding to the investigation without placing responsibility on the participants to describe the fine details their environments. This novel ethnographic method increased the knowledge of the researcher through engagement and sharing lived experiences within the participants' ecological environments.

The MIEF also provided a trustworthy way for a single researcher to participate and make decisions from the center of the research project universe. The MIEF allowed the researcher to accept *interpretive authority* and to be solely responsible for how the participants were represented within the study. The study proved that a single researcher could participate in every photo-sharing

discussion, record and transcribe every interview, examine and document every photograph after discussions, build trust and rapport with every participant, visit the communities of the participants and over a period of weeks, learn about the participants through engagement to better understand their social networks and neighborhoods. The MIEF deepened the knowledge of the researcher through ethnographic engagement and the development of trust among vulnerable people.

The MIEF is an improvement over both traditional Photovoice methodology and Interpretive Engagement, which often fail to provide a systematic and retraceable method of a combined thematic and visual analysis. Often considered a weakness in community-based participatory research, the analytic steps between data collection and the presentation of findings leave evaluators without the ability to follow the process from inception through findings. The MIEF provided a transparent and retraceable method for re-analysis from the original participants' quotes through to the selection of participant photographs. The MIEF increased the reliability and trustworthiness of visual findings. The development of Capitol Themes and Capitol Works showcased the superordinate themes and the most meaningful photographs along with the associated participant quotes and meanings. Together, the Capitol Themes and Capitol Works were member checked in stage three to ensure that the sole researcher had accurately unified the themes and works as collective research findings. This contribution to visual methods increased the trustworthiness of results and empowered vulnerable and marginalized groups to engage honestly in collaborative research endeavors.

Conducting research among PWUD exposed vulnerable individuals to potential risks. The MIEF protected the anonymity of the participants, had no group meetings, required little to no travel to destinations and allowed individuals the freedom to schedule meeting at their own pace. There was no pressure to take photographs of particular subjects beyond the broad topic of drug use. Participants were enrolled only after a local gatekeeper formally consented to participate as a primary source of protection should issues of

concern arise for the participants that they may have felt uncomfortable speaking to the principal researcher about. Flexibility in the design and implementation of the MIEF allowed for participants to reschedule meetings, have extra meetings or participate in meetings at locations they chose to add a level of comfort and enjoyment to their personal discussions about drug use and life experiences. Twenty-five PWUD completed exit interviews and all reported positive experiences with taking photographs and discussing their lives with opioids.

The MIEF was used successfully with PWUD and can be used for visual analysis of research topics with other marginalized groups. The MIEF provided several benefits to investigations with people from marginalized groups including the ability to participate in researcher-participant meetings independently, allow the inclusion of cohort members who to have and express strong views, protect vulnerable members for peer intimidation and allow for all participants to openly discuss difficult and revealing issues. The MIEF allowed for flexibility in working with vulnerable and marginalized groups as the researcher-participant meetings could also be done as small groups, divided by age, gender or any other way needed to protect the ability of the participants to openly share their knowledge with the researcher. The MIEF can be used successfully to meet with some participants independently, while meeting with others in groups who share common perspectives. The MIEF can be used successfully for visual analysis by people who do not speak the same language as the researcher. The MIEF was developed to avoid the shortcomings of the Photovoice methodology, while bringing increased transparency and trustworthiness to a true visual researcher-participant collaboration.

7.5 How the Findings Provided an Authentic Look at older PWUD and Contributed to Existing Research

The findings from this research provided an authentic and in-depth look at the lives of older PWUD through direct engagement and collaboration within the

investigation, without specific demands. The use of this qualitative visual research design allowed the participants to answer how and why questions on their terms through both photographs and conversations, which brought greater detail, thought and humanity to their answers.

The older PWUD in this study brought unique details of their experiences to the investigation and discussed a wide array of topics that, along with other participants, informed the researcher about personal issues that were found to be of great concern. The findings revealed a universal fear of homelessness and detailed how past experiences with problematic drug use had affected their lives. The visual findings revealed issues such as the extremely high rate of physical and sexual assaults against the female participants, the extremely high rates of ACE experiences and the alarming rates of recidivism. The findings revealed that participants experienced racism, discrimination and intimidation by law enforcement often, specifically when identified as a homeless individual or a rough sleeper who used opioids in both Liverpool and New Haven.

Most importantly, the visual findings humanized the participants and allowed these older PWUD the opportunities to lead the conversations and participate in the education of the researcher in matters of opioid use, homelessness and imprisonment. The findings detailed in photographs, how the participants' own experiences with opioid use could be used to identify institutional obstacles that impeded access to health services and the structural factors that supported recovery goals for individuals. It is the author's opinion, that this visual research framework sets a new standard for the level of depth, detail and authenticity that can be revealed by engagement and planning for collaborative ethnographic research with older PWUD.

The findings contributed to the existing body of research of older PWUD and expanded the use of visual research methods among this population to deepen the understanding of the experiences of older drug users which is lacking in previously published literature. Older people who use drugs have been a particularly difficult population to research as the literature identifies

several impediments to participation in health-related investigations. This visual methodology expanded the opportunities available for researchers to collaborate with vulnerable people in community-based participatory research projects.

This study identified many of the same issues that have been found in previous published research studies of people who use drugs. However, this study design was found to allow greater detail and depth to the answers provided by the participants by increasing the opportunities to share both words and photographs. This expansion in the way PWUD can communicate their experiences and perspectives through making photographs allowed their voices to transcend traditional verbal descriptions. The use of participant-generated photos as a discussion topic, provided an opportunity for the participants to revisit both the image and the conditions or experiences that led to the decision to capture the image. As both collaborators and photographers, the participants gave both visual and narrative answers to a multitude of how and why questions, and provided a greater insight and sharper details about the life experiences of older drug users. They explained how they were affected by homelessness, imprisonment and trauma and how these issues overlapped and compounded already dire circumstances for older people who use drugs.

Visual research studies such as this should stand as high quality examples of how partnerships with vulnerable and marginalized populations can be developed to answer drug-related questions and help solve health-related problems.

7.6 Recommendations for Policy Changes

Prior to final submission of this thesis, The Vagrancy Act of 1824 (5 Geo.4.c,83) was repealed on 28 April 2022 as part of the Police, Crime, Sentencing and Courts Act of 2022. The Vagrancy Act was used to arrest and imprison rough sleepers. The outdated and offensive law is no longer enforceable and follows a continuing trend throughout Europe to abolish laws

that criminalize and discriminate against people based on economic disadvantage.

In 2013, Connecticut passed SB896, The Homeless Persons' Bill of Rights to protect homeless individuals' rights as a protected class who may not be discriminated against in employment, housing or public accommodations. It allows homeless individuals the right to free movement in public spaces without harassment by law enforcement. In 2022, only the states of Rhode Island, Illinois and Connecticut have enacted legislation to codify the rights of homeless individuals. Currently, grassroots campaigns see the potential for passage of similar, Homeless Persons' Bill of Rights laws in California, Oregon and Vermont in 2022. The author recommends a federal policy change to enact legislation and pass a nationwide Homeless Bill of Rights. The author also recommends extending the right of homeless individuals and families to access government sponsored physical and mental healthcare as a way to provide comprehensive assistance to those people most in need.

The author recommends a federal policy change to Section 1905(a) of the Social Security Act, which prohibits federal Medicaid funds from being used to pay for services for inmates remanded in public institutions. Section 1905(a) was enacted in 1965 to exclude inmates even if they are otherwise eligible to participate in Medicaid when out of prison. This section of law is known as the Medicaid Inmate Exclusion Policy (MIEP) and should be removed from federal law immediately. Currently, there is not majority support in Congress to end the MIEP.

The US Bureau of Prisons (BOP) continues to violate section 504 of the Rehabilitation Act of 1973, which is intended to prevent discrimination of inmates on the basis of disability. As OUD is considered a diagnosable chronic disease in the DSM-V, the US BOP is in violation of prohibiting the use of OST/MOUD for the long-term treatment of non-pregnant individuals with OUD and for failing to conduct timely assessments of incarcerated individuals for OUD while in prison. The author recommends that Section 504 be strengthened by Congress and enforced to allow people in prison access to

OST/MOUD immediately. Currently, there is not majority support in Congress to enforce section 504 of the Rehabilitation Act of 1973 to improve access to OST across all federal prisons.

Lastly, Article 12 of the International Covenant on Economic, Social and Cultural Rights, provides that the human *right to health* is widely recognized worldwide to exist within and among other human rights, which affords all people to the right to the highest attainable standard of physical and mental health. The *right to health* was adopted by the NHS under the 1946 National Health Services Act and continues to be used as an example of an inalienable right throughout the UK and Europe. It is the author's recommendation that the words and intentions of Article 12 be adopted nationwide in the US and that federal policy change result in the enactment of a universal health insurance program in the US that provides access to healthcare for citizens and legal visitors as continues to exist throughout the UK.

7.7 Limitations of the Study

Several limitations existed within the investigation. Among them were the inability to generalize the findings to the populations of Liverpool and New Haven or to the wider UK and the US populations of older people who use opioids. This study was conducted among two small groups of individuals from two locations, which limited the opportunities to recruit a more demographically diverse group and expand the variation in potential participant experiences. Two larger international cohorts may have diversified the participant populations further and increased the opportunities to learn from and experience additional cultural communities in Liverpool and New Haven.

A limitation was the recruitment strategy of using gatekeepers to introduce participants into the study. The use of gatekeepers for the protection of both the researcher and participants brought limitations to the study by narrowing the opportunities for older people with opioid use issues to be recruited.

Gatekeeper bias against seniors, people of color and others may have played a role in participant selection by gatekeepers, limiting their inclusion. Alternative recruitment strategies or the use of additional gatekeepers may have provided a greater number of unique individuals and potentially the ability to reach saturation on certain key issues within the study.

Another limitation was the duration of time the researcher was able to interact with each participant. Having an extended calendar may have led to additional opportunities for researcher-participant interactions and the development of additional topics of investigation, stronger collaborative bonds, greater likelihood for phenomenological events of interest to occur and increased opportunities to detail those experiences related to long-term opioid use.

A limitation was also the lack of multiple participants over 60 years old. As identified in the literature review, there exists a lack of previously published research on older people and their experiences with long-term opioid use. The lack of previously published research was evident when researching older people who use opioids by gender: older women were much less likely to have been included in published drug dependence research for reasons that remain unclear. A greater number of female participants in this investigation may have uncovered additional unique findings that pertained to gender issues, sexual violence and motherhood.

No study is without the potential for researcher bias, including in the researcher-participant relationship and the environmental factors that frame the relationship. Limitations may have existed in the use of a single researcher. The study may have benefitted from multiple investigators, increased project duration and increased funding.

Lastly, there existed a limitation in technology and tools. Recent advancements in cellphone communication have brought the ability to text, talk and send pictures quickly. Although the population recruited was older and limited in their access to these new technologies, the research cameras could be replaced with better technology so that the interactions between

researcher and participant were more frequent, the pictures more vivid, the batteries always charged, the communication pathways more available and the conversations more frequent. Overcoming these technological limitations could be done through the use of a larger research staff and more financial support for the distribution of research cellphones. In this study, the cellphones were problematic to the IRB, as the cameras constituted an item of value and could have placed unnecessary risks on the older participants.

7.8 Suggestions for Follow-Up Studies

Follow-up studies to this research should include participants of significantly older age and include an equal number of female participants. Follow up studies would benefit from investigating *end-of-life* issues and the relationship with long-term problematic opioid use as well as alcohol and other drugs. Issues of accessibility to the illicit opioid economy for older people was a topic to be explored in senior housing as sex workers frequently target affluent institutions and used illicit drugs as a way to entice men into reconnecting days or weeks later. This study found that senior men who use illicit drugs may be specifically targeted by sex workers and drug dealers for victimization in both Liverpool and New Haven.

Follow-up studies should explore the potential to use grandparenting as a therapy for drug dependency. Grandparenting was found to encourage older PWUO to stop or decrease drug use behaviors. Grandparenting should be studied for the potential to mend broken family relationships, increase family stability, improve self-perception and instill happiness.

Follow-up studies may benefit from a larger enrollment population from a wider geographical area and include more women to diversify the participant population and their experiences within contrasting ecological environments. Urban vs. rural locations have been identified in the literature as bringing unique logistical and cultural issues to intersect with illicit opioid use. Rural communities may have fewer health services and likely pose additional

accessibility problems for older people who use opioids and seek drug services.

Follow-up studies may also benefit from the enrollment of a group of gatekeepers, social workers and mental health specialists as participants to learn from professionals who understand the experiences of the older people who use opioids. Specialists may provide a keen understanding of problematic opioid use based on their interactions with people who use drugs, the services that they access or are unable to access, the medications they use or are unable to access and the housing conditions under which they live.

7.9 Chapter Summary

This thesis was successful in investigating the experiences of older long-term opioid users and answering research questions about how and why opioid use complicated the lives of older drug users in Liverpool and New Haven. The use of the novel qualitative research framework which combined participant generated photographs and participant interviews as Capitol Works provided an effective and detailed way of understanding the differences and similarities between cohorts in Liverpool and New Haven.

This chapter detailed the effectiveness of the methodology and the methods used to gain an understanding of the participants' experiences. This chapter addressed how the fundamental differences between the experiences of older PWUD in Liverpool and New Haven were deeply rooted in the historical political policies and social fabric of the UK and US systems.

This chapter addressed how the research findings provided an authentic and in-depth look at older PWUD in Liverpool and New Haven and how the findings contributed to the existing body of research. This chapter provided a discussion of the methodological contributions this research had on older PWUD, contributions to visual methods research and contributions to research among vulnerable and marginalized groups.

Lastly, this chapter ended with a discussion of the limitations of the research investigation, suggestions for future research and the legal policies that currently exist in 2022, which have been implicated in this paper and should be changed to improve the health of older opioid users, including the right to access affordable health care for people who use opioids in the UK and USA.

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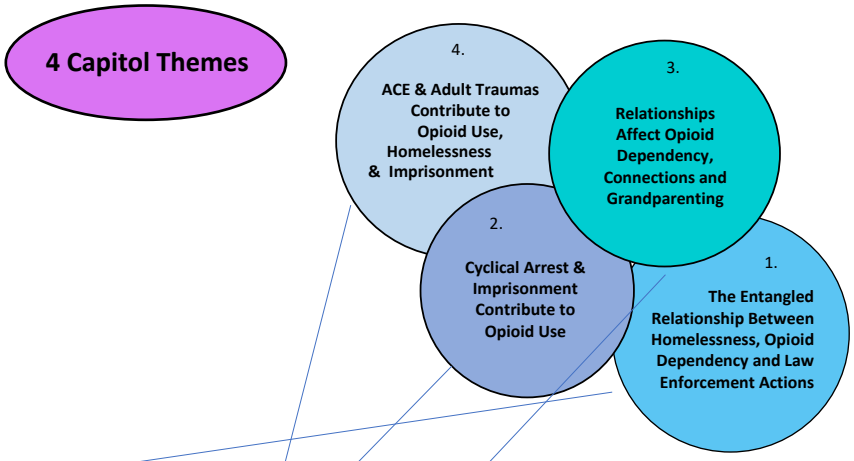
Appendices

Appendix 1: Capitol Themes and Descriptions



THEME ONE Broad homelessness remains a consistent and significant problem in both Liverpool and New Haven, a consequence of a combination of factors including; the availability of illicit drugs, problematic illicit drug use, economic instability, joblessness, fractured relationships, social hardships, traumatic life experiences, cyclical imprisonment and participation in criminalized activities. Rooflessness, couch-surfing, rough sleeping and housing instability were found to contribute to problematic drug and alcohol use, adult trauma, arrest by law enforcement, hopelessness, social isolation and risk for suicide. The conditions of broad homelessness existed among older people who used opioids in Liverpool and New Haven and were associated with the frequency of law enforcement interactions. Healthcare services and drug treatment opportunities in New Haven and to a lesser extent in Liverpool, often failed to adequately address and remedy the complex issues surrounding the triad of broad homelessness, physical and mental health needs and opioid dependence.

THEME TWO Jails and prisons were described and experienced as a form of abstinence-based drug treatment, as a repository for stigmatized and marginalized people punished for drug use and as a form of temporary housing for people better served by mental health care and hospitalization. Re-arrest and cyclical imprisonment were stigmatizing and had lasting stigmatizing impact on an individual's ability to participate in the community, enter the job market, participate with family, acquire housing and qualify for financial assistance.

THEME THREE Relationships both positive and negative, significantly affected opioid use in complex ways and shared a significant overlap with adverse childhood experiences (ACE) and adult traumas, which appear within *Global Theme Four.* Personal connection to grandchildren was strongly associated with healthy living and as a motivating factor for achieving recovery goals among participants in Liverpool and New Haven. Engagement with family through the role of grandparenting was found to foster re-connection in broken family relationships, increase opportunities to earn trust through responsible behaviors and actions, improve self-esteem and self-confidence and counter depression by eliciting happiness. Some participants who experienced social isolation and hopelessness also described estrangement from family, friends, grandchildren and work due to lost trust through lying, deception and secrecy related to opioid use, suggesting that meaningful interpersonal connections to others, including family members is beneficial to health.

THEME FOUR As acknowledged in Global Theme Three, there was a significant amount of overlap between the categories of relationships and adverse childhood and adult traumas as these two experiences coalesce around myriad human interactions which can potentiate experiential responses and also conversely, how lived experiences can potentiate human interactions. Adverse childhood experiences (ACE) and adult traumas contributed in complex ways to participant opioid use through the accumulation of negative lived experiences that are predictive of opioid use and opioid dependency. Participants described experiencing issues of abandonment, assault, the death of a loved one, rough sleeping, broken relationships, chronic physical pain, social isolation and physical, emotional and psychological abuse which negatively affected their lives and predisposed them to illicit drug use. ACE and adult trauma categorization and quantification was often a poorly understood health evaluation method among the New Haven participants, while participants from Liverpool had more experience and understanding of basic ACE surveys.

Appendix 2: 22 Lower-Order Organizing Themes of Thematic Network Analysis

"Distinct Principles and Predominant Ideas"

1. Rooflessness doesn't happen when you run out of money, it happens when you run out of relationships. (1)
2. Shelter system power dynamics use stigma and discrimination for placement, causing some to opt to sleep rough. (1)
3. Rough sleeping experiences further issues of stigma, discrimination, victimization, desperation and hopelessness. (1)
4. Lack of meaningful employment prevents individuals from accessing healthcare services. Healthcare is not a right in the USA. (1,2) (no job no healthcare→ jail). Employment can prevent cyclical prison sentences.
5. Criminal activities earn money / drugs. Survival strategies include criminal behavior when someone is homeless and sleeping rough. (1,2)
6. Prison living is described as better than sleeping rough for people who use opioids long-term (ex. rules, power, crime, abstinence). (1,2)
7. Without a job or a method of support, the shelter system is the only option for survival, unless you return to prison. Unemployment, shelter use and recidivism are stigmatizing. (1,2) (ex. spiral downward) Theses issues promote hopelessness.
8. The justice system is an unequal and oppressive institution of power that victimizes people who use opioids (ex. incarceration not offering drug treatment. (2)
9. Prison and jail are stigmatizing and limit an individual's ability to make positive changes to health conditions. (2) (ex. spiral downward)
10. NFA or No fixed address is stigmatizing, prevents job opportunities and increases risks of recidivism, homelessness and rooflessness. (2)
11. Prison and jail are used as a form of abstinence-based treatment for problematic opioid use instead of treatment services. Healthcare is not a right in the USA. (2) (healthcare→ jail)

12. Grandparenting is future oriented and allows distance from a person's past mistakes (ex. History). Grandparents can impart useful knowledge to grandchildren. Grandparenting causes happiness. (3) Good grandparent skills can mend broken relationships
13. Grandparenting is a family connection and an opportunity to mend connections and address ACE and adult traumas. (3)
14. Grandparenting offers an opportunity to rebuild trust and model responsibility to adult children who have experienced the consequences of a parent who uses opioids while attempting to parent. (3)
15. Grandparents are tasked with raising their children's children in situations where problematic opioid use effects parents with kids. Grandparent custody is often better than the institutionalization of at-risk children. (3,4) (ex. child custody)
16. Hopelessness causes overdose and risk of suicide, occurs when there is failure to cope with the stress, anxiety and traumas of life lived with problematic opioid use. (4)
17. Social pressures to use drugs are caused by peers, family members, stress, social networks, environment and exampled behavior (4)
18. Sexual assault experience is common among females with experiences of problematic long-term opioid use. (4) (ex. vulnerable rough sleepers, sex workers)
19. Adverse Childhood Experiences were often caused by exampled opioid or polydrug use - learned by observation and eventually become acceptable social behaviors. (4)
20. Drug sales, violence and physical and mental harm are accepted social and cultural realities in the community risk environments of Liverpool and New Haven. (4)
21. Veterans in the USA get higher quality medical care, drug treatment services, housing benefits, medication assistance for drug dependency, group counseling, and talk therapy. (1,4)
22. NHS is strongly appreciated as providing a good service to older people who use drugs. (ex. Methadone, No Second Night, Prison OST) (1,2)

Appendix 3: Thematic Network Analysis Map, Original

Thematic Networks Analysis Map

By Mark McRiley, 2019

Appendix 4: Demographic Data: UK Participants

	1	2	3	4	5	6	7	8	9	10	11	12
UK: Participant: ID	AA	SW	GP	PT	PW	DM	JL	CB	JO	LV	PJ	CE
Age	61	54	52	55	54	59	52	52	51	56	55	51
Gender	F	F	M	M	M	M	M	M	M	F	M	F
Methadone Script Experience	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	Y
Incarceration Experience	Y	Y	Y	Y	Y	Y	Y	Y	Y	N	Y	Y
Roofless Experience	Y	Y	Y	Y	Y	Y	N	Y	Y	N	Y	Y
Rough Sleeping Experience	N	N	Y	N	N	Y	N	Y	Y	N	Y	Y
Drug Treatment Experience	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Problematic Opioid Use	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Current Access to GP	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Mental Health Accessibility	N	Y	Y	Y	N	Y	Y	Y	Y	Y	Y	Y
Children Experience	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Current Housing Experience	F	F	P	G	G	F	G	G	G	G	G	G
(*GFP: Good Fair Poor Scale)												

Appendix 5: Demographic Data: USA Participants

	1	2	3	4	5	6	7	8	9	10	11	12	13
USA: Participant: ID	LC	MR	RW	RPL	RL	RT	DR	BG	OS	BW	TE	JJ	LB
Age	51	60	52	54	54	55	53	56	52	61	55	51	53
Gender	F	M	M	M	M	M	F	M	M	M	M	M	F
Veteran Status / VA Experience	N	N	N	N	N	Y	Y	Y	N	Y	N	N	N
Methadone Script Experience	N	N	Y	N	N	N	Y	Y	N	Y	N	N	Y
Incarceration Experience	Y	Y	Y	Y	Y	Y	Y	Y	Y	N	Y	Y	Y
Roofless Experience	Y	Y	Y	Y	N	Y	Y	Y	Y	N	Y	Y	Y
Rough Sleeping Experience	Y	N	Y	Y	N	N	N	Y	Y	N	Y	Y	N
Drug Treatment Experience	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Problematic Opioid Use	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Current Access to GP	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Mental Health Accessibility	Y	N	N	N	N	Y	Y	Y	N	Y	Y	N	Y
Children Experience	Y	Y	Y	Y	Y	Y	Y	Y	Y	N	Y	Y	Y
Current Housing Experience	F	P	P	P	G	G	G	G	F	G	F	P	F
(*GFP: Good Fair Poor Scale)													

Appendix 6: Participant Consent Form

The Health, Wellbeing and Recovery Needs of Older Opiate Users: A PhotoVoice study in Merseyside, England and Connecticut, USA.

Consent Form for Participation in PhotoVoice Research

You are being asked to participate in a PhotoVoice project. This project is being conducted as part of a research project on the social, cultural and environmental factors that influence health. The principal investigator is Mark McRiley, a post-graduate research student at Liverpool John Moores University, Centre for Public Health. Please feel free to contact Mark McRiley at m.m.mcriley@2016.ljmu.ac.uk. The project is funded in part, by LJMU, Centre for Public Health.

The purpose of this investigation is to identify the differences and similarities in the health, wellbeing and recovery needs of older opiate users in two sites; one in the USA and one in England. The study will examine differences in the treatment provision and wider social support for older opiate users and identify which strategies provide the most favourable outcomes to the study participants and the differences between the UK and USA policy systems. The investigation will identify the obstacles to treatment strategies and wider support services and compare the differences between the two locations. The research will enable participants to express their experiences through picture taking, dialogue and conversation.

Your involvement as a participant will consist of attending a series of five individual discussions to process and discuss pictures taken by you. With your permission, the discussions will be recorded for analysis purposes and presentation. These recordings will be used to transcribe the meetings and the transcripts will be read for themes in the analysis process. Your name, and any other identifying features, will not appear on the transcript. At each meeting, you will decide on a photo assignment to be completed for the next session. These assignments will be decided upon you and will focus on some aspect of your life experience & your health. You will attend one introductory session on camera skills and PhotoVoice methods for taking good quality pictures, and receive your first photo assignment. We will meet again weekly, where we will discuss the previous assignment and decide on another photographic task. After the second discussion, you will continue to take photographs independently for 3 weeks. Af At our fourth discussion, the digital cameras will be collected. You will be given GBP 50 for your involvement in this project and invited to participate in a showcase of the collected and printed photographs from the project. This event will include local community members and serve to introduce the results of the PhotoVoice project to the community. It is expected that the project will be done in five weeks, weather permitting.

Your participation in this research project is completely voluntary and you can refuse to answer any questions or you can leave before the end of the duration of the project. If you

decide not to answer some questions or leave early, your decision will not affect your relationship with the University, any services you receive or the researcher in any way.

Every effort is being taken to protect your identity. You will not be identified in any report of this study and the only people who will be included in discussions are you, other participants, the researchers, and assistants. You can choose to use a fake name and your real name will not be written down anywhere. Each meeting will be recorded so that it can be transcribed and possibly used for documentary purposes. You can refuse this or you can choose to not participate in any or all recordings at any time. If you agree to be recorded, your name will not be on the recording. All data will be kept in a locked file cabinet and accumulated transcripts and written materials will be destroyed after three years.

The benefits of participation will help this researcher, and others, develop relevant and effective strategies to improve the health and service needs of opiate users in your community. The only risk to you in participating in this group might be that you feel anxious talking about something personal and the time you spend here may take you away from other activities.

By signing below, you agree to participate.

_____ _____

signature date

Appendix 7: Gatekeeper Consent Form

LIVERPOOL JOHN MOORES UNIVERSITY
GATEKEEPER INFORMATION SHEET

The Health, Wellbeing and Recovery Needs of Older Opiate Users: A PhotoVoice Study in Merseyside, England and Connecticut, USA

Name of Researcher: Mark McRiley
School / Faculty: Centre for Public Health, Dr. Gordon Hay, Dr. Conan Leavey & Dr. Jean Breny

1. **What is the reason for this letter?**
You are being asked to participate in a photovoice project to identify the differences and similarities in the health, wellbeing and recovery needs of older opiate users. Your facility provides access to this unique group of participants and we would like to collaborate in research to learn about the specific service needs, obstacles to treatment and the strategies which provide the most favourable outcomes to opiate misuse.

2. **What is the purpose of the study/rationale for the project?**
The purpose of this investigation is to identify the differences and similarities in the health, wellbeing and recovery needs of older opiate users in two sites; one in the USA and one in England. The study will examine differences in the treatment provision and wider social support for older opiate users and identify which strategies provide the most favourable outcomes to the study participants and the differences between the UK and USA policy systems. The investigation will identify the obstacles to treatment strategies and wider support services and compare the differences between the two locations. The research will enable participants to express their experiences through picture taking, dialogue and conversation.

3. **What we are asking you to do?**
We would like your participation in guidance, experience and facilitation of gatekeeping up to 16 participants. These participants will meet the researcher weekly to discuss submitted photographs that pertain to their lives and their personal experiences with opiate sobriety or opiate addiction.

4. **Why do we need access to your facilities and staff?**
Your facility and staff have access to a population of people who may meet the inclusion criteria for this photographic research project. We are looking for 16 men and women over the age of 50 who have at least 10 years of experience with opiates. Participants do not currently need to be taking opiates and inclusion in the study only requires past experience with opiates in one or more, of it's many different forms.

5. **If you are willing to assist in the study what happens next?**
If you are willing to assist in this community-based participatory research study please contact principal researcher Mark McRiley at email address: m.m.mcriley@ 2016.Ljmu.ac.uk. The principal researcher would be happy to come to your facility to discuss the project in depth and answer any additional questions you may have.

6. **How we will use the Information/questionnaire?**

This Photovoice project is focused on photographic submissions from the participant

photographers and allows for the photographs to lead the group's weekly discussions. The standard 5 question, S.H.O.W.e D. questionnaire provides a standard opening route of dialogue between the participants and prevents misinterpretation of the submitted photographs. The photographer provides the narrative that describes each photograph presented to the group. Over the first 4 weeks of the project, participant photographers will submit up to 3 pictures per week, resulting in a collection of approximately 100 or more pictures for analysis. All submitted photographs remain the property of the photographers. Each photographer will be provided a copy of his or her original works at the end of the project. Each standard 5 question S.H.O.W.e D. questionnaire will be combined with the specific photograph to ensure the photograph and accompanying narrative remain enmeshed for further data analysis. All photographs and accompanying narratives will be studied using thematic analysis for comparison.

7. Will the name of my organisation taking part in the study be kept confidential?'

Should your organization choose to participate in this photovoice project, all participant names will remain confidential and at no time will the names of participants be connected to the photographs or the questionnaires. Additionally, at no time will the names of the organizations be used and confidentiality will be maintained for the duration of the photographic project. All data will be coded and stored in a locked cabinet in the LJMU Centre for Public Health.

8. What will taking part involve? What should I do now?

Please sign and return the **Gatekeeper Consent Form** provided, or contact Mark McRiley at m.m.mcriley@2016.ljmu.ac.uk. We will make plans to meet in person to discuss any additional questions you may have.

This study has received ethical approval from LJMU's Research Ethics Committee in April, 2016.

Contact Details of Researcher	Mark McRiley, m.m.mcriley@2016.ljmu.ac.uk
Contact Details of Academic Supervisor	Dr. Gordon Hay, g.hay@ljmu.ac.uk

If you have any concerns regarding your involvement in this research, please discuss these with the researcher in the first instance. If you wish to make a complaint, please contact researchethics@ljmu.ac.uk and your communication will be re-directed to an independent person as appropriate.