

**Exploring the Experiences of Injecting Drug Users  
Living with Leg Ulceration: A Qualitative Design**

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## **Abstract**

There is a paucity of scientific evidence into the lived experience of people who have a history of injecting drug use and are living with leg ulceration. Portraying the true voice of injecting drug users (IDUs) through narrative means is a novelty in contemporary literature. The representation of the life and the person behind the leg ulcer, having experienced addiction, is original from a purist narrative perspective. This study, led from the perspective of a nurse-researcher leading in the field of wound management, offers a unique opportunity to gain a rare glimpse into the daily life of IDUs, as reported in their own words.

The aim of this study was to explore the experience of injecting drug users living with leg ulceration using qualitative methodology.

A naturalistic paradigm framed the design by allowing participants to control the data in an unrestricted and open manner without direct intrusion from the researcher. Qualitative methodology was central to collecting data on life experience and feelings.

The ethics process detailed a rigorous application to explore the professional, ethical virtues from the perspective of an insider-outsider working with sensitive data in a marginalised population.

Diaries were kept and recorded by participants over four weeks in their routine daily life; this was followed by semi-structured interviews. The diaries allowed a unique insight into the past, present and future of IDUs and how their ulcer affected their lives. The diaries also facilitated a means of reflection on themselves and their wounded body. The interviews offered an opportunity to explore in detail the diary entries and other stories participants wished to share.

The study recruited twelve participants from leg ulcer clinics set in London; three women and nine men older than 18 years of age (median age of 52 years; range 35 - 62 years). Ten completed the data collection process; two of the participants, aged 61 and 62 years, were married. Gatekeepers working with IDUs with leg ulceration were central to the process of engagement and recruitment. Participants welcomed the design as an opportunity to voice and share their journey of living with an open wound.

The findings revealed the detailed suffering participants endured living with their ulcer: pain, shame and stigma were clearly voiced in their narratives. The majority of

participants had experienced some form of stigma during their life and this was exacerbated as they were drug users. The self-blame and punishment triggered by this felt stigma was a detriment to the health of participants. Those in contact with specialist wound care services saw a significant improvement in wound healing and this had a positive impact on their wellbeing and their overall outlook on life. Participants also voiced enacted-stigma experienced from encounters in health practice. These negative experiences exacerbated the self-stigma. Findings also portrayed the multiple characteristics and talents of participants including humour, art and resilience.

This research contributes to science and practice by understanding the lives of IDUs living with leg ulceration. It provides a platform from which to engage both generalists and specialists who care for these patients and has the potential to influence medical and social policy-making and clinical practice in this field. By means of narrative inquiry, this study may challenge the conventional social stereotypes, the taboos and the stigma still experienced by this patient group in health care.

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## Statement of original authorship

The work contained in this thesis has not been previously submitted to meet the requirements for an award at this or any other higher education institution.

To the best of my knowledge and belief, the thesis contains no material previously published or written by another person except where due reference is made. I certify that I have complied with the rules, requirements, procedures and policy of the University.

Name of candidate: Jemell Geraghty

Signature: \_\_\_\_\_

Date: 2<sup>nd</sup> March 2018

## **Chapter One: Introduction**

### **1.0 Introducing the study**

The subject of my research is the daily lived experienced of leg ulceration in the injecting drug user population. The methodology chosen for this study were diaries conducted over four weeks, followed by semi-structured interviews involving the same cohort of participants. The study was set in London and involved ten adult participants being current or ex injecting drug users (IDUs) (seven males and three females, two of the participants were married). Adopting the role as nurse-researcher meant I was known to the participants in a clinical capacity as a nurse specialist in the field of leg ulcer care and tissue viability. The purpose of the study was to explore the experience of living with a chronic wound; set in a naturalistic paradigm by means of qualitative methodology using data collection by diary entries then digitally-recorded semi-structured interviews. The findings within this study have the potential to inform current service provision of leg ulcer care for this population and develop the relationship between patient and clinician.

This chapter will introduce the background for the study and the justification for undertaking the research along with the overarching research aim(s) and objectives. The chapter will conclude with a summary of the remaining chapters of the thesis and a personal reflection from the author.

### **1.1 Key figures**

In order to appreciate the individual and organisational cost, impact and long term health implications of leg ulceration and injecting drug use within the National Health Service (NHS), the two conditions must first be recognised as independent detriments to health. People who inject drugs (PWID)\* are susceptible to a number of viruses and infections associated with this method of administration. Injecting drug use can result in high morbidity and mortality rates. Recent figures from Public Health England (PHE) reported “ between 2015 and 2016, 203,808 people received treatment for drug misuse in England with an estimated 40% of those were currently or had previously injecting drugs” (PHE, 2017a, p. 6). A major complication for those that inject intravenously in the veins of the lower limbs is venous leg ulceration. Chronic venous leg ulcers are a debilitating, painful and costly wound condition (Kapp & Santamaria, 2017).

*\*Recently the term People Who Inject Drugs (PWID) has been used in the literature as a synonym of Injecting Drug Users (IDUs). Therefore, the two acronyms have been used interchangeably.*

The numbers affected by drug use in England, United Kingdom (UK) demonstrate the gravity of the problem. In recent years, there is an estimated population of 293,879 opiate/crack users in England with 193,192 adults in contact with treatment services. Only 29,150 of them (15%) completed the drug treatment free of dependency. A growing concern is the number of under 18 year olds accessing substance misuse services: in England alone it is estimated at just over 20,000 (PHE, 2016). The social and economic cost of drug supply in England and Wales is estimated to be £10.7 billion a year; from 2015-2016 around 2.7 million (8.4%) of 16-59 year olds reported taking a drug in the last 12 months. In this time 203,808 people received treatment for drug misuse although there was a drop in attendance significantly in the last 10 years, mainly among first time treatment encounters under 25 year olds who were heroin users. There has also been a dramatic increase in drug related registered deaths, with heroin fatalities having more than doubled from 2012 to 2015 (UK Home Office, 2017). Beynon et al. (2009) previously showed the long-term effects of injecting on the physical and mental health in a small number of IDUs aged 50 years old or over, representing the growing chronicity of the condition in the older, veteran drug user. This, along with other work, has highlighted a growing number of drug users of this age group within many large cities in the UK (Graham et al., 1999). As IDUs age, their general health care needs to be aligned with their drug misuse to ensure a treatment plan later in life (Higgs & Dietze, 2017).

The government aimed to spend an estimated £1.2 billion in 2009-10 to challenge drug use, with the overall objective of bringing down the cost to society of £15 billion a year (UK National Audit Office, 2010). The Home Office ten-year drug strategy (2008-2018) aims to restrict the supply of illegal drugs by reducing the demand while focusing on protecting families and strengthening communities, tackling drug-related crime and anti-social behaviour and preventing harm to families affected by drug use. The overall aim is to provide new methods of social rehabilitation involving communities by reintegrating former and current drug users into communities using housing, education and employment (European Monitoring Centre for Drugs and Drug Addiction - EMCDDA, 2005; UK Home Office, 2008).

This research project aimed to show that consideration should also be given to the lived experiences of IDUs with chronic leg ulcers. Chronic leg ulcers have been shown to inhibit social integration by isolation, loneliness and depression, that in turn can delay wound healing (Ballard - Wilson, 2004; Cole – King & Harding, 2001; Jones et al., 2006). The impact of policy on ordinary people does not always have an immediate result. The more complex the issue, as in the case of drug use, the higher

the risk to overlook some practical aspects of care such as basic wound diagnosis, treatment and prevention. Frontline staff play a pivotal part in ensuring policy is shared and implemented in a fast and effective manner. They have a key role in connecting with hard to reach groups such as PWID to ensure policy is fulfilled. Answering the question of how to capture the experiences of IDUs living with leg ulceration proved the diary methodology to be a powerful research tool to portray the stories of those who live remarkable lives in often difficult circumstances.

## **1.2 Drug use: the cost**

As well as the physical cost of injecting there is also the price of buying the drugs. It is estimated in the UK that one gram of cocaine (powder form) costs approximately £42, with crack rocks (form of cocaine made into small lumps/rocks) costing between £10 and £20. There are many variations in the price of street heroin sold as “brown” and bags can be sold at £10 with some consumption costing anything up to and over £100 a day (Frank, 2016). The Times Educational Supplement (2011) reported the concerning casual use and experimentation that young people, some only 15 or 16 years old, are undertaking with heroin, although the method of administration was not specified; the cost of purchasing heroin has dropped by half and the drug can be bought at a street value of £5 a fix, meaning it is now no more expensive than cannabis, resulting in a rise in young people trying it.

The financial and social implications of using illicit drugs are devastating and what can begin as a casual habit often quickly becomes an addiction. A cascade of social events can quickly follow and often include: mental health problems, unemployment, homelessness, potential criminal prosecution and imprisonment and the breakdown of the family network (Craig & Hodson, 2000; Hammersley et al., 2007; Neale, 2001; Neale & Stevenson, 2015; Reid & Klee, 1999).

## **1.3 The pathophysiology of intravenous drug use**

Injecting illicit substances remains one of the most hazardous forms of administering drugs. There are a number of immediate dangers associated with injecting including the risk of overdose, infection and injury to the blood vessels and surrounding tissues. Drugs that are commonly injected include heroin, cocaine and amphetamines. Methods of injecting consist of intramuscular, subcutaneous or

intravenous self-administration; the process of injecting correlates to the rapid onset of the effects of the drug (Pates et al., 2005; Rassool, 1998).

The potential of a vascular injury to the blood vessels of the limbs is significant when injecting and increases with repeated use of the same site. IDUs often inject into the veins in the lower limb, particularly the groin, when all other routes of access are exhausted. Repeated injecting into the lower limb veins results in chronic venous insufficiency (CVI), a progressive regurgitation of the superficial and/or deep venous systems that may lead to vein obstruction. Clinically, CVI can present as varicose veins, leg swelling or oedema, heaviness of the legs and/or ulceration (Fiddes et al., 2010).

There are several risk factors for CVI and ulceration within the IDU population including repeated vein and leg trauma, collapsed veins and deep vein thrombosis (DVT); however little attention has been given to venous disease in IDUs and even less is known about the psychological impact of venous ulcers in this group (Pieper et al., 2000). CVI is a commonly reported medical condition, not specific to the IDU population, with a number of associated risk factors including; age, gender, occupation due to long hours standing, family history and obesity (Beebe-Dimmer et al., 2005). CVI persists in IDUs even after injecting ceases and ulceration may occur at any time, even after prolonged periods free from injecting (Pieper et al., 2009). Other well documented medical complications associated with injecting include; bacterial infections, abscesses, Human Immunodeficiency Virus (HIV) / Acquired Immunodeficiency Syndrome (AIDS), pseudoaneurysm, endocarditis and arthritis (Stein, 1990). The focus of this study is with IDUs who have previously injected into the lower extremities causing repeated damage to the lower limb blood vessels, particularly the veins, nerves and muscles resulting in venous leg ulceration.

#### **1.4 Justification for the study**

A preliminary review of the literature demonstrated that there was a small body of work on the care of leg ulceration in IDUs. Despite the prevalence of published literature concerning leg ulceration, little is known about the IDU population and, in particular, how IDUs manage their leg ulceration and how they feel about leg ulcer services (Charles, 1995a, 1995b; Walters et al., 1999). In addition, the psychosocial impact of venous ulcers on quality of life and personal insight of this group remains, to some extent, hidden (Pieper et al., 2000). This research aims to add valuable qualitative data to an area where only a small body of evidence has been published

and to meet the call of many authors advocating for further studies (Finnie & Nicolson 2002a, 2002b; Palfreyman et al., 2007; Pieper 1996a, 1996b). The purpose of this study is to learn from IDUs personal journey and experience, to contribute to existing theory and understanding about leg ulceration in this population. This study is unique in that it will provide IDUs a diary to allow them freedom to express feelings and report their personal experiences of living with a leg ulcer. The diaries were followed by semi-structured interviews to further explore the lived experience narrated in the memoirs. This study is aiming to deepen the understanding of this chronic disease by relating possible psychosocial factors that may influence care or healing.

### **1.5 Research: question and aims**

The appropriate methodology fulfilling the research design was investigated with the view of identifying the most practical, efficient and unobtrusive means of collecting data from IDUs. The following question and aims were used to structure the design of the study.

#### Question:

What are the experiences of injecting drug users living with leg ulceration?

#### Aims:

1. To explore the experiences of IDUs attending leg ulcer clinics.
2. To examine IDUs experiences of having a leg ulcer and how this impacts on their quality of life.

Overall the findings of the study have the potential to raise important issues about the delivery of care and service experiences for IDUs; highlighting successes, challenges and possible failure of services.

### **1.6 Living with a leg ulcer: capturing the story**

The journey of living with a leg ulcer from the perspective of an ex or current injecting drug user gives us a unique insight into their daily life of living with an open wound. Diaries are a powerful means of capturing the lived experience of the individual in their own words. By providing a means to document ones journey and reflections, diaries can provide valuable data for understanding the daily activities, feelings and

relationships of IDUs. In researching how best to capture the experience of IDUs life, diary methodology was considered the least invasive of all other qualitative methodologies and the most user-friendly, practical method of collecting data (Ross et al., 1994). The ability to tell stories makes life meaningful and interpersonal by exploring the personal accounts, words and language of the individual to project a new light around their experience. The process of narrating life by recounting experience will allow participants to make sense of their existence by reflecting on their personal narrative (Taylor & Francis, 2013).

### **1.7 Narrative inquiry**

The research perspective that informed and guided this study was based on a qualitative approach set in a naturalistic paradigm by process of narrative inquiry. Narratives are stories that present the unfolding of events, human actions or sufferings from the perspective of an individual's lived experiences. A narrative approach is firmly grounded in qualitative traditions and emphasises the significance of the lived experience (Muller, 1999). Narrative permits the presentation of experience holistically in all its complexity and richness (Webster & Mertova, 2007). The themes captured within the diary and interview data will be constructed as narrative using the words of IDUs themselves to give real voice to the story.

People who have a history of substance misuse often show extraordinary physical and emotional resilience. The experience of what makes us resilient is unique to the individual and further research is needed to provide a clear understanding of the role of marginalisation and resilience coping in a clinical treatment context; paradoxically for some, the experience of marginalisation may enhance resilience (Hopwood & Treloar, 2008, p. 25). Both injecting illicit substances and experiencing chronic leg ulceration have a profound physical impact on the body, often resulting in long-term health problems, and a social impact on the individual. Together, they present a population externally injured by the wounds that disfigure their legs while internally laboured with the damage of their addiction. Often considered by the wider social world as vulnerable, IDUs are frequently nomadic in terms of accessing services for their wound care. The voices of these individuals may have the potential to positively influence the way we care and establish services for leg ulceration by understanding the experience shared and the story told.

The data collected within this study presents a pragmatic way of approaching and accessing the lived experiences of this group. We may gain insight into the way

people manage their wounds and how they construct life, living with an open ulcer on one or both legs. We may also understand the unique relationship people have with their wounds, how the sight, odour and pain experienced impact on their identity.

### **1.8 Organisation of the study**

The next section presents a personal reflection on my story through the Doctorate in Health Research (DHRes) programme and a background to my interest in this research topic. To share a narrative is to become one with it and it was important to demonstrate my place within the story.

Chapter two provides a review of the literature, which included the evolution of the UK drug problem and the physical and psychosocial implications of drug use. It will explore the generalist view of IDUs and the concept of stigma as a detriment to health for illicit drug users. The review will explore the impact of living with leg ulceration with specific reference to leg ulcer care in the IDU population.

Chapter three presents the research methodology and details of the study design. The study consisted of two phases of data collection. This chapter also discusses the ethical challenges of undertaking research with vulnerable participants.

Chapter four presents the findings of the study by presenting a biography of each of the participants followed by a closer exploration of the data from the diaries and semi-structured interviews.

Chapter five is a critical discussion of the findings, analysing the contribution of the narrative of IDUs living with leg ulceration in line with the current evidence. The chapters will conclude by considering the contribution of my research to theory and practice. The limitations and recommendations are also addressed with the view of identifying areas for further study.

### **1.9 Personal reflection**

My nursing career to date, spanning over 17 years, has allowed me to care for some of the most complex patient groups within primary and secondary care. The concept of caring for the sick, the vulnerable and those in pain has formed the cornerstone of my practice. Fundamentally, health care should be provided to all individuals in a compassionate and equal manner and professionals should be equipped with the

skills to work with groups of patients whatever the complaint or circumstance. However, my clinical experience has taught me that this is not always the case and that patients that fall outside the box of the so called general population often fall short. It is my belief that the majority of these cases are not due to lack of empathy. Quite simply clinicians are not often equipped to deal with patients who have a history of injecting drug use who present with leg ulceration. This can lead to feelings of frustration and uncertainty for both the patient and the clinician. The practical challenges of assessing and treating IDUs, particularly when they are in the hurricane of their addiction, is by no means an easy task; however, the task is not impossible and not without reward. My work published in *Emergency Nurse* highlighted some of the practical ways of managing leg ulceration in patients with a history of injecting illicit substances (Geraghty, 2015a - Appendix 1). Far from popular belief, people who have injected drugs and have leg ulcers neither like coming to Emergency Departments nor do they want to be admitted to hospital for endless days, away from their surroundings and normal routine. They come to the acute doorstep when they need help or feel unwell. They do not want to be bedridden on a ward waiting for their methadone prescription that may never arrive.

The most important part of this research was to portray the person behind the story, to allow the characteristics of the individual to reach out and resonate with the reader. If we can look beyond the stereotypes and truly experience the person then we can make a connection.

As part of the Florence Nightingale Travel Scholarship 2012, I had the opportunity to explore leg ulcer services for IDUs throughout England with emphasis on London and Northern England, including Sheffield, Birmingham and Stoke on Trent. This constituted an opportunity to visit and witness first-hand the different clinical services for IDUs with a particular focus on leg ulceration. My report has been published by the Florence Nightingale Foundation (Geraghty, 2012a) and was reflected on in the *British Journal of Nursing* (Geraghty, 2015b - Appendix 2). This experience marked the beginning of my story and with this came the increasing awareness of the ethical implications for caring for this client group. The concepts of trust and virtue are central to the care of all patients and formed the foundation of my research from start to finish. These ethical characteristics are pivotal to both research and professional integrity; I explore these notions further within the methodology chapter. We may live different lives in the same world, having chosen different paths; however, we are ultimately all human beings, exposing similar vulnerabilities to life's hurdles. I fundamentally believe that we are all connected by our weakness and vulnerability.

For those who fall on the path of addiction, the road is long, hard and often very lonely. Healthcare workers have a duty to care for those who need us; we must be patient and tolerant and be willing to offer another chance to the vulnerable patient who did not attend a medical appointment; maybe there was a reason; maybe he or she had to walk 40minutes to get there in bandages. Telephone and ask, build that relationship.

The impact of this study has been powerful, as I have learnt to value people for who they really are, with all their rich complexities and wondrous characters. Professionally, I am privileged to share my journey with other practitioners, externalising and enhancing this personal experience. I still reflect and feel privileged to be allowed into the lives of such vulnerable people: they, despite having previously had poor experiences, nonetheless, trusted me with their story. It has opened my eyes to the harsh reality: stories of social and cultural inequality, stigma and yet resilience. How is it conceivable in this modern age of scientific wonder that people who need our empathy and kindness still experience poor health practice? This has to change.

Sharing the stories of IDUs with leg ulceration offers the opportunity to learn and grow, provided that we are willing to listen. Finally, I would like to share one of my stories, an insight into why it is important to present this work:

*I was approached by one of the senior doctors on a busy ward about a lady who had been admitted with a leg ulcer. He said to me "Can you possibly see this IDU with a leg ulcer in Bed 20"? I replied... "For sure ...Does the lady have a name?" He smiled shyly at me with a look on his face...a second of reflection perhaps...I raised my eyebrow and smiled... "Sure sure" ...he said and quickly gave me her name.*

## **Chapter Two: Literature review**

### **2.0 Introduction**

This chapter presents a review of the literature that explored the experiences of injecting drug users living with leg ulceration. In order to understand the lives of people with wounds as a result of having injected drugs into the lower limbs, it is important to appreciate the wider context of both drug use and leg ulceration. This review established what was already known about the phenomenon within the sociological and medical literature, the rationale behind the research question and the current focus on professional practice. The medical and nursing fraternity tends to focus on the clinical complaint as a priority while in mental health and social care this may not be the immediate concern of work. This has left areas of practice, such as leg ulceration in the IDU population, an unknown territory for multidisciplinary professionals. Generalists manage the wounds but are often at a loss regarding how to manage the complex psychosocial needs of the service user; mental health and substance misuse specialists can address these issues but are often unsure how best to manage wound care.

Many elements of the study were reviewed including drug policies and the social, political and economic determinants of health focusing on injecting drug use in the UK. It also included an investigation of the literature related to the physical and psychological implications of drug use and wound care. This was to support the professional contribution of the study with a view to improve the wound care experience and service provision for drug users with leg ulceration. In line with the change and growth of drug use and service needs, the review explored in depth the attitudes, experiences and understanding of clinicians to substance misuse and their perception of a drug user. In conclusion, having provided an insight into drug use, the literature explored in greater detail the concept of spoiled identity and in particular stigma as a detriment to health for drug users.

### **2.1 Search methods**

The literature review aimed to capture key issues in the evidence surrounding the experiences of IDUs living with leg ulceration from a wider context of care. This included the psychosocial, political and health evidence associated with the various components of the research question. The holistic embodiment of a relatively new and emerging topic required the collection of literature to be flexible and inclusive

(Torraco, 2005). The conventional systematic review of the evidence would not capture the literature in a manner best suited to address the research question. Furthermore, the rigidity of a systematic review would not include all potential sources of evidence in a way that was open to emerging concepts and ideas of the topic. A systematic review of the literature would have focused solely on the research question and would not have included the various dimensions required of this study. The hierarchy of evidence was not restrained to Randomized Controlled Trials (RCT's), meta-analysis or intervention; rather it was conducted in a manner that tried to generate emerging evidence in a comprehensive way which addressed the research question from all potential points of the social science perspective (Bettany-Saltikov, 2012). Critiquing the evidence in such a way required an assimilation of the literature in an open manner, including all disciplines of the social and medical worlds.

### **2.1.1 Integrative review**

An integrative literature review was considered the most thorough and useful among search methodologies. The research question itself did not fit neatly into a systematic framework. As the study matured, so did emerging themes and sections within the evidence. The concept of the narrative of IDUs living with leg ulceration meant presenting the literature in a comprehensive and undiluted manner. A systematic approach proved too rigid for the research question. The integrative review has significance and interest across a number of disciplines: nursing, infectious diseases, vascular surgery, mental health and social care as well as general practice and the social sciences. With this in mind, the review aimed to “tell a story” through the specific lens of a nurse-researcher having explored the social and physical implications of a population not widely represented in the field of wound management or general practice (Torraco, 2005 p. 361). An integrative review of the literature was chosen to present the various components of this study in a way that generated new knowledge and provided the same lens in which all disciplines involved could look upon this topic from a new perspective (Torraco, 2016).

Overall, throughout the six-year programme of study, the DHRes provided a structured learning curriculum that supported the various elements of the research question. These learning options included: Social, Political and Economic Context of Research (SPECR), Research Proposal Development, Introduction to Qualitative Research with an option to progress to Advanced Qualitative Methods, Quantitative methods and various research workshops, student presentations and even seminars

from leading experts in health research. I applied these learning areas and activities to explore the various details of the intricate research question at different levels: psychosocial, physiological and socio-political. As a result, the search strategy to support the integrative literature review evolved over time. The review consisted of three separate search frameworks with new and developing key search terms, adapted as the emerging themes matured, to depict in full the wider evidence associated with this study. The search strategy, in general terms, will now be discussed alongside the individual search frameworks that supported the structure of the overarching sections of the integrative literature review.

### **2.1.2 Search strategy**

The databases were searched individually within the specific limits with the objective of having presented a told story to address the research question and the broader sociological elements surrounding this design. The research question was: *what were the experiences of injecting drug users living with leg ulceration?* The complexity of the search required an understanding of the overarching policies, practice and opinion which related to the disciplines of wound management, health care and social policy. To explore the literature in a way that was comprehensive and relevant required the search strategy to develop as new knowledge about the phenomena emerged.

The objective of each search was to present the evidence, past and present related to the clinical and sociological experience of leg ulceration and substance misuse. Once a background to the design had been presented the search aimed to capture the wider issues of the question which included stigma and the identity of the wounded person sharing their story. This would add depth and meaning to the proposed qualitative methodology and the analytic framework of narrative inquiry.

#### Databases and search limits

The electronic search databases used for the literature search included PubMed and Medline which allowed access to peer reviewed, worldwide health literature. CINAHL plus to include nursing and allied health literature which incorporated access to books and dissertations, government documents and standards of practice. The latter was a valuable resource particularly for identifying qualitative research studies (Chapman, 2009). The Cochrane Library, recognised as the epitome in the hierarchy of evidence, endorsed the importance of compression therapy as the gold standard in the treatment and prevention of venous leg ulceration (Nelson & Bell-Syer, 2014;

O'Meara et al. 2012). The Scopus database also complemented the search with abstracts and peer-reviewed literature that included scientific journals and books. These core resources were used to ensure the literature covered a significant proportion of all the available published and unpublished literature while identifying the most contemporary research. Furthermore, websites such as Google Scholar and Infomine were integrated within specific limits; these limits included UK, European and American studies involving humans written in the English language.

The overall timescale for the review was set from 1960 onwards; the need to capture evidence from this era became evident by using an integrative approach, a key advantage of adopting this method of literature search. Throughout the literature review the reference lists of selected studies were also explored to broaden results using snowball sampling and hand searching of specific journals was also undertaken (Polit et al., 2001).

### **2.1.3 Search Strategy – Phase one: the background**

As the research question began to take shape, the first part of the literature review reflected the period of exploration and understanding of the wider issues associated with drug use. Within this first phase of the review, the search framework aimed to explore the historical, social and political climate of drug use in the UK from 1960 to present. Previous research had shown major recognition, growth and changes within the IDU population particularly in relation to legislative measures, treatment and the impact on society from 1960 onwards (Bewley, 1965a, 1965b; Bewley & Ben-Arie, 1968; Bewley, Ben-Arie & James, 1968; Hewetson & Ollendorff, 1964; Spear, 1969; UK Ministry of Health, 1967; UK Ministry of Health and Department of Health for Scotland, 1961, 1965). As a result, this time period was chosen as the starting point to ensure issues surrounding experiences of IDUs and service provision at the time were highlighted. Furthermore the 1990s witnessed major advances in the management of patients with leg ulceration with new services emerging to bridge the gap between hospital and the community while embracing the multidisciplinary approach (Moffatt et al., 2007; Ovens, 2006; Stevens et al., 1997). For the first search the key terms were *intravenous, injecting, illicit substances, drug, leg ulcer, venous, service, cost, perspectives, as well as Medical Subject Headings (MeSH) terms experiences, drug user, policy, addiction and wound.*

### **2.1.4 Search Strategy – Phase two: stigma and identity**

As the study evolved, the literature developed to reflect the new concepts that were emerging with the design. The era of the 1960s also captured the seminal work of Erving Goffman (1963) *Spoiled Identity* exploring the concept of stigma and identity. This literature helped form an understanding of how marginalised populations in drug use feel about identity, living with open wounds and in turn how they perceive the world around them. It also added depth to the overall experience of this wounded group of individuals. For this search key MeSH terms were used *substance misuse, drug, stigma, attitude, prejudice and health care* along with searching key authors within the social stigma and labelling literature for example *Goffman, Scambler, Link and Phelan.*

### **2.1.5 Search Strategy - Phase three: the key areas**

The categorisation of literature into distinct areas became apparent early in the research. The first was the social, physical and psychological implications and challenges of both injecting drug use and chronic venous ulceration and how this impacted on the individuals' quality of life and the health service and moreover how this was measured. The second was the attitudes, experiences and understanding of clinicians to substance misuse, how this influenced care and was reported in the literature. The third area related specifically to leg ulcer care in the IDU population; this evidence, although valuable in content, was insufficient in quantity and it was produced by a limited number of authors; this, again, emphasised the need for further studies combining these areas. The final phase of the review included literature from authors such as *Palfreyman, Pieper and Coull, formerly Finnie*, established names in the IDU leg ulcer research.

The literature surrounding these core concepts included the impact on society and on the individual drug user; this was embodied in the design, having explored the concept of stigma and the mechanisms by which the individual in society can be constructed and deconstructed by stigmatising attitudes and experiences.

### **2.2 Evolution of UK drug problem**

Within the literature, emphasis was placed on exploring the causes of injecting drug use, the growth of heroin addiction, the impact on society of illegal drug use and the treatments provided by health care professionals. As part of the programme of study for the DHRes this work was published in the *British Journal of Nursing, Drug policy, intravenous drug use, and heroin addiction in the UK* (Geraghty, 2011 - Appendix 3). It was important to understand and present the early policy and growth of addiction in the UK in order to appreciate the current implications on health and social care. Up to April 2013 drug and alcohol treatment in England was managed by the National Treatment Agency for Substance Misuse (NTA), which became part of PHE, an executive agency of the Department of Health (DOH) (PHE, 2017b). The UK Focal Point on Drugs based at PHE together with the Home Office and other government departments publish annual reports on the UK drug situation. Focal Point on Drugs is a national partner of the European Monitoring Centre for Drugs and Drug Addiction (EMCDDA) (PHE, 2017c).

According to a recent published report, heroin has remained the most harmful of drugs to society, causing significant devastation to the health and social wellbeing of users. In 2015, 59,763 people presented for treatment reporting opioids as their main problem with heroin being responsible in 85% of the cases. The population of opiate users is aging taking into account the rise in heroin users during the 1980s and 1990s. This is clinically relevant in patients that present with lower limb complications and ulcers, despite being many years clean from injecting. Importantly, since 2003/04 the percentage of primary heroin users entering treatment over the age of 40 has almost trebled; in 2015 this rose from 10% to 35% (PHE, 2017c). The UK Home Office (2016) published key findings regarding numbers of drug users with around 1 in 12 adults aged 16 to 59 having taken a drug in the last year which accounts for around 2.2 million people in England and Wales. Over one-third of adults within this age group had taken drugs at some point in their lifetime, an increase from 30.4% compared with a survey in 1996.

### **2.3 Physical and psychosocial implications of drug use**

The serious medical complications surrounding heroin addiction are historically well documented as drug addicts were prone to a multitude of infections caused by the use of unsterile needles, syringes and drugs (Holzman & Bishko, 1971). Louria et al. (1967) reviewed the literature around self-administration of heroin by analysing 100 episodes in 96 patients observed while hospitalised. The reported complications included endocarditis, pulmonary complications, hepatitis, tetanus, overdose and abscesses at the site of infection, cellulitis, thrombophlebitis and bacteraemia. Such a detailed study, however, failed to explore or even mention the psychological implications of heroin abuse; this is indicative of that time in medical practice. While the impact of injecting is recognised in relation to hyperpigmentation over veins, thrombosed veins and resulting lesions/ulcers and infections, the link at this early stage had not been made in relation to treatment of venous ulcers from a practical or emotional level; more interest appeared to be on the materials used for injecting and the resulting infections rather than on the individual themselves (Dunne & Johnson, 1972; Henriksen et al., 1994; Orangio et al., 1984; Vlahov et al., 1992). It should be noted that the above studies were conducted in the United States of America (USA) and Denmark by medical practitioners in surgery, microbiology and infectious diseases.

One of the first papers to highlight the profile of injecting drug use in the 1980s within the UK was conducted by physicians working in Accident and Emergency (A&E) departments in Edinburgh. Dunlop and Steedman (1985) showed that there was an increase in the IDU population which coincided with the rise in patients attending A&E as a result of injecting drug use. Over a four-month period a total of 92 patients attended with 104 new complaints. A total of 78% of all patients were under 30 years of age at the time of presentation and approximately a quarter were female. The vast majority of patients presented with trauma, 65% of whom had an unspecified “open wound”. This paper was valuable as it highlighted wound care in the IDU population; however, it failed again to demonstrate any possible connection between IDUs attending A&E and the psychological issues surrounding wound care, drug usage or possible overdosing. The authors, at the most, describe IDUs attending A&E as having “unpredictable behaviour and poor compliance” (p.77).

### **2.3.1 Blood-borne viruses: a change in literature**

The real change in literature and governmental directive relating to injecting drug users came to effect in 1986 with the outbreak of a potential HIV epidemic among the injecting drug user community. The first case of AIDS in an IDU was reported in March 1985; by 1986 and 1987 reports from Edinburgh, Scotland suggested high levels of transmission of HIV among drug injectors and this became a new focus for public health and governmental concern. Injecting drug users were seen as a potential threat, contributing to the spread of HIV to others (Stimson, 1995). Promptly, local authorities and UK government agencies committed to providing free needles and syringes to IDUs. This programme, more commonly known today as *harm reduction*, aimed to reduce the frequency of shared needles and syringes among IDUs with a view to reduce the risk of spreading blood-borne viruses (BBVs) such as HIV and Hepatitis C (HCV) (Hutchinson et al., 2000). Stigmatisation of IDUs in health care settings was shown to be a direct barrier to receiving Antiretroviral Therapy (ART) and Opioid Substitution Treatment (OST) with treatment providers often ill-equipped to manage addiction and thus regarded IDUs as troublesome or non-concordant (Wolfe et al., 2010).

The public emergence of HIV and other BBVs had a profound effect on the way IDUs were perceived at the time and the stigma associated with the condition is well documented. Stigma resulted in the misconceptions about the cause of transmission of BBVs and its association with illicit drug usage (Butt et al., 2008). In Western

countries the morality of injecting drug use was heavily policed and it was strongly linked to illegal activity and seen as an indicator of multiple forms of social distortion in the legal, moral and health world (Treloar & Rhodes, 2009). Certain groups of drug users were found to have faced a double jeopardy: drug use and homelessness; drug use and maternity. Homeless people were found to be stigmatised not only by health professionals but by other IDUs for their circumstance. This raised a number of negative implications for IDUs wellbeing and self-worth affecting their engagement with harm reduction and similarly other important services such as ante and postnatal care (Simmonds & Coomber, 2009). Stigma has also been shown to be greater in those who have a substance addiction, including alcohol, combined with mental health problems than in persons with a mental health condition alone. Mental health was rarely considered and injecting drug users were held morally accountable for their actions; socially they provoked rejection from the general public (Schomerus et al., 2010).

Preventing the spread of BBVs was a key health issue for PHE (2017d) to ensure the health and safety of injecting drug users and the wider community. Prevention of BBVs transmission benefits the general population by reducing the risk of health harms related to injecting drug use and the associated costs. Engagement has played a crucial part in ensuring that IDUs access and connect with specialist services; this comes with the understanding of their experience of living with addiction and the social effects of drug use such as homelessness and mental health issues. PHE (2013) recognised the value of ensuring a successful first contact with users to optimise their personal experiences as key to their engagement and best care. Treatment services that have created a good first impression, provided in a welcoming and non-judgmental manner, were more likely to have service users return if they have been treated well by staff in a comfortable environment. The importance of human touch and everyday good manners in carrying out procedures was pivotal when working with vulnerable groups of people such as IDUs. Treatment based on empathy, understanding, respect and the ability to listen were among the trademarks of services that retained their clients (Ashton & Witton, 2004).

It became apparent that the literature around specialist services addressing the stigma of injecting illicit drug use was well established. However, the literature addressing harm reduction, mental health and addiction was still limited in the field of general health practice.

## 2.4 The generalist view

The perception and the care of IDUs in general practice, particularly secondary care, was sparsely documented in contemporary literature. Early evidence presented a robust attempt to measure the attitudes and beliefs of health care professionals and patients to substance abuse, including alcohol and drugs, using methods such as questionnaires (Berger–Gross & Lisman, 1979; Caplehorn et al., 1997; Potamianos et al., 1985). Carroll (1993) highlighted that the majority of earlier research focused on the approach of professionals in the field of drug abuse came from American scholars, with a clear gap in UK-based studies. This advocated a call for further research into the effects of healthcare professionals' personal views on the delivery of care. In 1998 the Royal College of Psychiatrists launched a campaign called *Changing Minds*, promoting the philosophy that society, including health care professionals, should develop a more open–minded and compassionate attitude towards drug and alcohol abuse with a view to reduce the associated stigma, social isolation and discrimination in this area (Lowe, 2000). More recent qualitative studies in Scotland showed that prejudice still existed; this emphasised the need for multidisciplinary working, education and further research to understand the clinician's mind-set working with drug users and how this impacted on care (Carroll 1996; Grafham et al., 2004; McKeown et al., 2003; Watson et al., 2006).

More recent literature focused on the gap between the clinical needs of IDUs and their substance addiction. Inadequate hospital pain management and the lack of specific knowledge by nursing staff on how to manage the associated behaviours of patients with substance addiction and concomitant pain remained a real issue (Morgan, 2014). This in turn impacted on the concordance of patients, their reactions and coping mechanisms.

Managing leg ulcer pain is a significant clinical challenge for practitioners working with IDUs. Depending on where in the journey people are with their addiction (recovery, maintenance, active use or a combination of all the previous stages), there is no single remedy that suits all. Pain is a complex phenomenon and the correct treatment largely depends on how the person assessing the pain perceives the person in pain. Pain is unique to the individual experiencing it and therefore the assessment and treatment should be patient-tailored. The multifaceted features of pain were explored as part of the literature review and published in *Wound Care Today* (Geraghty, 2016 - Appendix 4).

Education on all levels for all specialties is central to informing care and influencing good practice. There have been repeated attempts to integrate the addiction framework into the general nursing curriculum. One study focused on 29 nurses recruited from medical acute units and medical wards in a large NHS Acute Trust in England to explore how nurses managed and delivered care to patients with drug use-related complications. None of the nurses within the study had received any formal pre-or post-registration training to equip them with adequate skills to deliver care for patients admitted with complications of drug use. Clinically they were able to meet the physical needs of the patients; however, they failed to deal with specific drug related needs such as the management of drug withdrawals (Monks et al., 2012).

The general health literature does not address the broader health care needs of IDUs such as chronic leg ulceration. This could explain why clinicians are often unprepared to manage the complexity of IDUs' clinical presentations. The question then arises concerning how this inability or failure to deliver the appropriate care may be related to physicians' attitude or behaviour and how this could be perceived by IDUs. The notion of stigma featured in the clinical and sociological literature prompted a further exploration of this concept as a potential detriment to the health of IDUs. Reviewing the literature on stigma exposed the various elements of the wounded drug user. It is necessary to question how both imagery and reality influence the ideas and experience of the afflicted and how the social world responds to this imagery. This led further to considerations on the appropriate method to capture the experience of IDUs in a sensitive and unrefined manner.

## **2.5 Stigma as a detriment to health for illicit drug users**

Medical sociology has a deep interest in the sources and consequences of stigma relating to detriments to health, which originate from the early seminal work of Erving Goffman (1963). Most of the published literature has taken this classic text as pioneering and focused on the notion of *stigma and spoiled identity* outlining its anthropological, sociological and psychological history (Scambler et al., 2006). Goffman's work remains a key focus today within sociological literature for those interested in the social forces that shape life chances and patient health care and is of relevance to the context of this study (Schnittker & John, 2007).

Stigma can be described as a mark, either physical or social, separating individuals from one another, based on a social judgement; stigmatised persons or groups are

somehow tainted and set apart from the norm in terms of appearance and behaviour. Such judgement often originates from negative beliefs or stereotypes based on prejudice, frequently leading to exclusion and avoidance. The World Health Organisation (WHO, 2012) explored treatment and prevention options for alcohol and drug dependence in 147 countries, highlighting how drug dependence has still not been recognised as a health problem in many countries and how stigma and discrimination associated with drug dependence have created major barriers to receiving appropriate care. According to United Nations (UN) estimates, there were about 230 million adults (aged 15-64) worldwide, comprising 5% of the adult population, who have used an illicit drug at least once during the year 2010; this included approximately 27 million people who already had a severe drug problem. Clarke (2001) introduced the concept of stigma as a social construction that can have a devastating impact on the individual and families with chronic health problems such as drug dependency; the author emphasised the importance for health professionals to realise how coping with social stigma may, in some cases, be more detrimental than coping with the illness itself. "...if health professionals want to maximise the well-being of the people they treat, they must address stigma as a separate and important factor in its own right" (Link et al., 1997, p. 177).

The stigmatisation of people who misuse illicit substances has significant consequences for government policy in terms of supporting reintegration, recovery and public health. Drug users are seen as both blameworthy and to be feared; as a result, they are subject to exclusion, labelling and discrimination in many areas. Stigma can prevent people who may have a drug problem seeking help as this would mean admitting to themselves and to society that they have an addiction, thus acquiring the mark of infamy. Drug users are expected by society to change their behaviours and practices; however, in return society has to take responsibility in promoting recovery and reintegration by better understanding the nature of addiction and supporting routes of recovery (UK Drug Policy Commission, 2010).

Medical professionals have long relied on social scientists to provide information around concepts of health and illness in marginalised populations due to medical conditions such as leprosy, mental health illness, HIV/AIDS or in the case of illicit drug users or sex workers (Opala & Boillot, 1996; Rosenfield, 1997; Weitz, 1990). Stigma can create a barrier for prevention and care for conditions such as HIV/ AIDS where HIV acquisition has been related to religious, cultural influences in the view that the acquisition of the virus was a consequence of immorality and shrinking marital responsibility related to promiscuity and immoral behaviour. This moral

stance could also be applied to illicit drug users whose habit could be viewed as immoral and unacceptable if BBVs were acquired through injecting drug use this could again be related to their so called irresponsible behaviour. Many people living with BBVs and those concerned that they might be HIV-infected often feared judgement and avoided health services for treatment or testing (Rutledge et al., 2009). Devine et al. (1999) commented earlier that AIDS-related stigma is inextricably intertwined with social identities and the motivation to maintain positive social character. The marginalisation of HIV/AIDS sufferers and drug users arises out of uninfected or unaffected people's need to protect their identity as healthy and nondeviant.

In an international study of attitudes towards 18 stigmatised health conditions, respondents gave higher stigma ratings to "drug addiction" and "alcoholism" than to "chronic mental disorder"; this is probably due to the fact that substance misuse is still largely associated with an immoral or inept lifestyle choice in which individuals are thought to be fully responsible for their actions and have deliberately chosen to behave in a socially unacceptable manner (Room, 2005). The sequelae of substance misuse may result in more stigmatised behaviours such as sex work, crime, homelessness and incarceration which have further impact on the needs of the individual in seeking health and social interventions (Buchanan, 2004; Shiner, 1995). Galea and Vlahov (2002) argued that social factors (socio-economic status, homelessness and incarceration) associated with drug use are not consequences but rather circumstances that are complex and intertwined with drug user patterns that inevitably shape the health of drug users. Neale et al. (2008) identified a range of barriers that injecting drug users faced when attempting to access generic health services and the attached stigma and negative attitudes of clinicians who often labelled them as "demanding" and "undeserving"; this could then result in non-concordance or defiance regarding care. Other negative attitudes included the presumed criminal behaviour of illicit drug users and also injectors' own embarrassment about their behaviour and what actions that may have taken place during the journey of addiction.

It is widely accepted that drug users experience high levels of social exclusion. Drug use and misuse is a stigmatised activity that differs from others discussed within the literature in one vital way, it is illegal. By law, illicit drug use is a criminal activity and is therefore bad; *ipso facto*, drug users are bad and rightly stigmatised and therefore risk societal ontological insecurity (Giddens, 1991). This is the cardinal difference between the stigma attached to drug use and many other stigmatising phenomena

and one that must be borne in mind when considering the stigma experienced by drug users (Hunt & Derricott, 2001). Stigma is not a singular concept expressed or felt in a common way; rather, it is a complex phenomenon expressed both subtly and overtly; it is unique, subjective and partially dependent upon the nature of the stigmatising condition and the social circumstances of the individual (Fife & Wright, 2000). Individuals who experience feelings of stigma may accept that their physical activity or behaviour is evidence of inferiority; however, others who experience such feelings may hold the belief that it is the negative reaction of stigmatisers rather than their own disreputable trait (Page, 1984).

Illicit drug misusers face both physical and psychosocial stigma: visually due to the wounds, ulcers and scars that cover their bodies and socially due to the exclusion they face as prejudice and isolation surrounding this chaotic yet resilient group of people (Ahern et al., 2007; Room, 2005). The need to understand substance misuse in its socio-cultural context and respond to the holistic needs of the population who misuse drugs cannot be overemphasised. Social prejudice, negative attitudes and stereotyping are widely held amongst health care professionals with drug users and may compromise the care they receive. As a result, health related problems may go untreated and may potentially be exacerbated (Hussein Rassool, 1998).

The concept of stigma in marginalised groups is reported extensively in the literature from a number of different perspectives. For the purpose of this literature review, two pieces of seminal work by *Erving Goffman* and *Graham Scambler* were critiqued and applied to the population in question.

### **2.5.1 Erving Goffman**

The concept of stigma itself is complex and elusive; this is clearly represented in terms of variance of definition within the social science literature. Goffman (1963) related its etymology back to the Greek word for “tattoo-mark” which refers to physical marks or signs that were used to represent the abnormal and bad about the affected individual’s moral position to the identifier. According to Goffman’s (1963) preliminary conceptions around stigma and social identity, society labels a person with a stigma as not quite human and ideology was constructed to explain the inferiority of the stigmatised, using differences such as social class and demeaning metaphors and language. Goffman (1963) distinguished between two types of stigmatised individuals: the discredited and the discreditable. Discredited individuals assume that others are aware of their differences or disability, while the discreditable

person has the opposite belief that his or her uniqueness is either unknown or not immediately apparent to others. Goffman notably identified ways in which the stigmatised adjusted or dealt with their differences. Firstly, there was the attempt by the individual to correct what was different about them and Goffman gave examples such as plastic surgery, therapy and education. A second strategy involved the mastery of some skill or area in order to overcome disability and difference (Franzese, 2009). Interestingly, in clinical practice patients who attend leg ulcer clinics often use humour to detract or compensate for the attention the ulcers may bring for example malodour, dirty bandages or limping due to the pain. This type of distraction and coping mechanism has been shown to be a valuable stress moderator at difficult times such as in the event of loss and trauma (Scott, 2007).

Goffman (1963) described three different types of stigma. First, the horrors and physical deformities of the human body. Second, the imperfections of character an individual may possess that are recognised as weak, uncontrolled passions, rigid and precarious beliefs, and dishonesty; including mental health disorders, incarceration, addiction, alcoholism, homosexuality, unemployment, suicidal attempts and extremist political behaviour. Finally, the ethnic stigma of race, nation and religion which can be hereditary and equally contaminate all members of a family. Goffman's categories of stigma can be applied to the illicit drug user population. The physical deformity and marking that injecting drug users bear are visible in the form of wounds, ulcers, abscesses and scars from injecting; the weakness of character or immoral behaviour from taking illicit substances is also clearly perceived with the consequences of such actions such as crime and possible incarceration. There is also the potential hereditary consequences of illicit drug use such as children of addicts being taken into care and future generations exposed to an increased risk of using drugs; furthermore, some babies may be born drug dependent. The concept of the discredited and discreditable individual also applies to this population. Quinn et al. (2004) add that those who cannot conceal their stigmatised identity, for example race; gender or physical disability must chronically cope with potential discrimination from others. For those whose stigmatised identity is concealable, possible devaluation can be avoided as long as the stigma is successfully hidden; for IDUs this is a difficult challenge when living with leg ulcers and bandages. People living with leg ulceration must endure the daily reality that they may encounter stigma. When the ulcer is leaking and malodorous, the stress associated has been shown to lead to low self-esteem and isolation, resulting in

anxiety and depression (Peart, 2015). This, combined with possible visible signs of active illicit drug use has the potential to increase stigma and negative emotions.

In an attempt to deal with the stress associated with feeling like discredited individuals, injecting drug users isolate themselves into subgroups trying to normalise their attributes, resisting and challenging the status quo and covering. Joking about a disfigurement or disability is an example of covering: it is an attempt to make “normals” feel comfortable (Joachim & Acorn, 2000). People who have a concealable stigma may be highly motivated to disguise it. Goffman (1961) has referred to this activity as “passing” and found that the ability to conceal a socially devalued aspect of the self, such as drug addiction or misuse, may be viewed by people with similar stigmas as highly advantageous in social interactions. It could help to minimise the impact of their stigma on others; however, to influence what is revealed and not revealed about oneself demands a great deal of mental control, which for some groups of people may prove difficult due to the physical or psychological effects of their stigma (Smart & Wegner, 1999). An example of signals or disclosure of identity that may lead to stigma in illicit drug users is the way they act. Many drug users have a history of mental health illness that may manifest as bizarre, inappropriate behaviour, language irregularities and poor social skills, which in turn can produce stigmatising reactions (Corrigan, 2000).

There are various ways to manage or conceal stigma, all of which involve the concealment of sensitive information; for example, a drug user can cover his legs and arms to hide scars and wounds and withhold information/history, which can be both as simple and elaborate as they feel. There is also a sense of embarrassment and rejection associated with ulcers and scars and often represents a story that may or may not wish to be told. Radcliffe and Stevens (2008) explored how drug users who had dropped out of treatment in England described their stigmatisation from health clinicians and within health services using qualitative interviewing. The authors referenced Goffman’s (1968) work around concealment of identity for the dishonourable person whose source of shame, if hidden, could allow them to possibly pass as normal. The interview data revealed that the management of identity involved a balancing act between the individual’s own sense of self and their belonging to a community.

Tribal stigmatisation of drug users could result in isolation and disownment from family or contamination of all members of the family and associates. Burns (1992) revisited Goffman’s stigma essay suggesting that physical or mental incapacity may

allow for actions and words which ordinarily would be inadmissible. This could lead to false statements or portrayals of incapacity such as childishness, physical incompetence or incapacity; the question then arose of how far the appearance of incapacity depended on a recognisable style of behaviour.

Adding to this Manning (1992) noted that stigma does not carry the same meaning for everyone and gave an example of the failure of a manager to obtain a degree as a stigma however for a criminal or drug user the presence of one may be equally stigmatising within their social group. In terms of judgements around substance misuse there are often many preconceived notions and prejudices around individuals who misuse illicit substances however substance use has no limits and can affect all individuals from all corners of society regardless of age, sex, race or religion (Miller, 1997). Room (2005) added that those who are stigmatised or marginalised are often poor however there is no necessary relation between stigmatisation and poverty or other social inequalities. It is possible to be rich and stigmatised and marginalised, although the well-off are *ipso facto* more able to purchase protection from this. We see in today's media a celebrity culture of chaos and tragedy around drug misuse. Londoners such as Amy Winehouse (1983–2011) and Peaches Geldof (1989 - 2014) tragically succumbed to drug addiction yet it could be argued they managed for the most to conceal the physical marks of their drug dependence. Money may buy the ability to physically mask the features of addiction for a time; however, the story behind drug use does not discriminate between social classes. A contemporary London comedian, Russell Brand, described his journey into heroin addiction and advocated the need to treat the person behind the stigma and not the illness. *"I cannot accurately convey the efficiency of heroin in neutralising pain. It transforms a tight white fist into a gentle brown, wave, and from my first inhalation 15 years ago it fumigated my private hell...The only way to help addicts is to treat them not as bad people but as sick people"* (The Spectator, 2013, para 1, 3). Stigma is not a myth conjured to describe a phenomenon that no longer exists; stigma is an ongoing reality and there is still much to learn from Goffman's original theory.

Since Goffman's seminal work (1963) a number of investigators have developed conceptual frameworks to study health-related stigma, applying various terminologies to several similar paradigms. One such framework, often referred to as the hidden distress model hinges on the core separation of *enacted stigma* and *felt stigma* (Scambler, 2009). Substance misusers in recovery face stigma in its various forms, including enacted, perceived, and self-stigma. Enacted stigma refers to the direct experiences of social discrimination which could include barriers to finding

employment and housing, limitations in terms of treatment and support services, or interpersonal rejection. Perceived stigma refers to beliefs that members of a stigmatised population, such as illicit drug users, have about the prevalence of stigmatising attitudes and actions in society. Scambler and Hopkins (1986) related enacted and felt stigma to epilepsy whereas enacted stigma referred to the discrimination against people with epilepsy on the grounds of their perceived unacceptability or inferiority. Felt stigma is more complex; principally it refers to the fear of enacted stigma but also encompasses a feeling of shame associated with being epileptic. In terms of living with concealed or spoiled identity relating to epilepsy, felt stigma was rarely triggered off by an episode of enacted stigma. Although the majority of people with epilepsy admitted to suffering sporadically from felt stigma, only a third could recall ever having encountered enacted stigma. The distinction between felt and enacted stigma is significant in terms of the relationship between the interactional and biographical aspects of stigma. The experience of felt stigma may also refer to an individual's fear of failing to enact a normal appearing round of life (Gray, 2002). Heslin et al. (2012) added that enacted stigma may apply to instances of prejudice or other forms of unconcealed rejection such as rudeness, hostility and avoidance. Felt stigma is a complex multi-dimensional concept that involves shame, embarrassment and anxiety about encountering enacted stigma. Felt stigma or self-stigma refers to negative thoughts and feelings for example disgrace, embarrassment or fear that emerge from identification with a stigmatised group and often results in avoiding treatments and isolating contact from others (Luoma et al., 2007).

Stigma not only harms the individual with an illicit drug dependency it also concerns the family and associates of the sufferer. Goffman (1963) called this *courtesy stigma*, the prejudice and discrimination that is extended to people not due to a physical marking but rather that they are linked to the individual by a stigmatised mark. Corrigan et al. (2006) used surveys to examine the impact of blame, shame and contamination of mental illness and drug dependency families who experienced stigma. Families reported being blamed for the onset of their relatives' condition, relapse and the view that their family member was incompetent; this in turn led to feelings of shame. Families with a relative who was dependent on illicit drugs were harshly stigmatised by the public in comparison to families with a relative with mental illness; the public was unwilling to endorse that family-stigma actually existed in order not to risk social disapproval. Courtesy stigma also known as stigma by association involves the disapproval of society on an individual, group or family

evoked as a consequence of associating with a stigmatised individual or group. People who bear a courtesy stigma are regarded by others as having a spoiled identity and are in an ambiguous situation in society. They are normal in their performance of conventional social roles yet their differences are occasionally manifested by their association with the stigmatised. Some who bear a courtesy stigma will accept those with a spoiled identity and convey this through their attitudes and actions while others will seek to erase all information of their association with the stigmatised (Birenbaum, 1970 p. 196). Courtesy stigma is the least studied of the three types of stigma: the negative consequences of association with a stigmatised individual can extend not only to close family and friends but also to those who are merely in their presence, leading to social isolation, rejection, avoidance and discrimination (Bogart et al., 2008).

Link and Phelan (2001) expanded on Goffman's social interactionist definition of stigma by conceptualising stigma as the co-occurrence of labelling, stereotyping and discrimination. Their definition has pushed the concept of stigma research further by exploring two additional areas (i) the translation of stigmas into broader sociocultural traditions and institutions, including social welfare policies and (ii) the interaction of stigmas with other determinants of health. Phillips et al. (2012) highlighted that social science literature on stigma is focused on those who experience stigma directly; however, he acknowledged Goffman (1963) who suggested that stigma not only affects the single individual but also those associated with them. Interestingly, relatively few studies have attempted to explore the impact on those who support stigmatised people. Parker and Aggleton (2003) add that studies of stigma should go beyond descriptive examination of attitude and expression and should explore further the function of stigma in maintaining social order by examining intersections of culture, power and difference in order for societies to promote what is desirable in terms of moral behaviour.

In terms of understanding the sociological literature on initiation into drug use, Payne (2007) referred to dispelling the concept of predisposition to addiction and promoting the influences of social experience while applying Goffman's (1959) idea of a deviant career in order to understand the processes of becoming an addict. Payne's work explored the initiation into heroin use in women drug users and found once women were labelled as deviant they normally became estranged from family and friends and their drug using careers often progressed to criminal activity; he further referred to them as deviants. Furthermore, should they become drug dealers they could gain a new criminal purpose and a new social deviant identity within their networks.

Crocker and Major (1989) added that individuals, who by virtue of their membership in a socially marginalised population such as substance misuse are vulnerable to being labelled as deviant, are targets of prejudice or victims of discrimination. On the other hand, this unique membership within such a group has been shown to protect one's self-esteem not only from injustice but also in some cases from daily setbacks, failures and rejection. Goffman (1963) noted the overuse of this self-protective attributional function of social stigma with respect to a variety of stigmatising conditions.

Simmonds and Coomber (2009) analysed how social stigma impacted on the injecting drug user population, how IDUs operated among them and the results this led to in terms of prevention and harm reduction amongst IDUs. They found that IDUs stigmatised other lesser IDUs. This was evident from the steroid injecting drug users who chose to separate their behaviour from that of the junkie heroin IDU. Furthermore, supposedly responsible IDUs who did not engage in risky behaviour condoned risky behaviour as likely to be carried out by lesser people, such as the homeless, lazy and those who "did not care". Projecting stigma to others was used as a medium to disregard their own focus of shame and risky behaviour by concentrating on the behaviour of others; this ironically turned against themselves: believing that they could be less scrupulous about their own behaviour, they exposed themselves at greater risk. Stigma can operate negatively and impact against and within the IDU population.

Strong (2008) reflected on Goffman's controversial style of sociology at the time and his simple belief in naturalism in that if we wish to find out what the social world is like we should go out and look. Somewhere he accused sociologists of standing too close to their instruments to be able to see. Smith (2006) explained that Goffman was not interested in the big questions about the nature and development of modern society. His interest was in the structure of face-to-face interaction, in the mundane of ordinary talk and activity. His sociology was not theoretically ambitious it modestly promoted description, classification and conceptual articulation. Goffman's theory rationalises stigma for the everyday person today and analyses what constitutes stigma and the segregation of people from one another and the world around them.

### **2.5.2 Additional views**

Although traditional views on stigma continued to influence current thinking forty years on, Link and Phelan (2001) revisited the concept of stigma and constructed a

revised conceptualisation of the term. Their definition of stigma exists when elements of labelling, stereotyping, status and discrimination happen together in controlled circumstances that allow these series of occurrences to unfold. Moreover, they suggest that stigma is likely to be a key detriment of many of life chances from psychological well-being to employment, housing and life itself. Stigma, and the extent to which it is successfully attributed and accepted, should be understood from the unequal (social) power relations within the context it operates.

Page (1984) noted that stigma assigned itself to one particular characteristic; stigma may change over time and gave an example of the unmarried mother in the early centuries due to the conduct which contravened the instruction of the Christian church. However, since the mid-sixteenth century the dependency of the unmarried mother on public aid has been the main reason for such stigma; more recently, due to the normalisation of the condition of the single parent in many societies, it could be questioned whether stigma for the unmarried mother no longer exists. It could be argued that this may apply for illicit drug use, provided some substances such as cannabis are legalised in parts of Europe and USA and their use is increasingly portrayed as acceptable by the mass media.

### **2.5.3 Graham Scambler**

Scambler and Hopkins (1986) early work concentrated on the impact of the condition epilepsy upon the lives of sufferers, with attention to coping strategies developed in the family and at work. This early paper also introduced a distinction between enacted and felt stigma with particular interest in epileptic sufferers' sense of stigma and its origins, properties and how it could have contributed to a disruption or imbalance of activity or lifestyle. One of the concepts addressed in this paper is the matter of disclosure and how although the majority of epileptic sufferers managed to conceal their diagnosis of epilepsy and therefore were not directly vulnerable to enacted stigma; they nevertheless had to live daily with the possibility of exposure. Exposure might occur through either stigmata or stigma cues; stigmata referring to the clinical manifestations of the condition such as seizures which could be noticed and lead to exposure. Stigma cues refer to events and happenings, excluding stigmata which are similarly noticed and ultimately a giveaway and examples could include absences from work, overheard conversations or witnessed drug taking. The policy of non-disclosure reduces the opportunity for enacted stigma with one crucial

consequence of this being that felt stigma, and the fear of enacted stigma is more disruptive to the lives of people with epilepsy than enacted stigmas.

Scambler (2004) acknowledged Goffman's pioneering work more than a generation later and highlighted the need to re-frame our understanding of stigma in light of substantial social change and restructure. Within the concept of re-framing stigma, Scambler made clear that this is presented as an ontological deficit. Parsons (1951) proposition of the sick role is referenced in part as a mechanism to control illness as deviance. The Parsonian model defined the sick role as a socially deviant status and in relation to institutionalised social expectations, sentiments and sanctions. Within the system of expectation relative to the sick role, the sick person is exempt from normal role and responsibility, depending on the nature and severity of the illness; the illness is not of his or her fault. Yet with the IDU population, who often live with multiple health conditions, this does not apply; the sick role does not excuse them from the stigma associated with their drug use.

The state of being ill is, in itself, undesirable and carries an obligation to get well and to seek help and cooperate in the process of getting well. The Parsonian model has problems for use in differing cultural groups and for dealing with a multitude of diverse physical and mental ailments. The model best suits temporary and acute, easily identifiable physical episodes of illness and is less applicable to other health problems such as mental health disorders and chronic conditions (Ablon, 2002; Pescosolido et al., 2008). Scambler (2004, p. 38) added that illness tainted with stigma provided another division and grounds for potential negativity: "not only does it constitute and afford opportunities for deviance but it is evidence also of deep inadequacy or imperfection in its bearer". Interestingly, the IDUs seen in practice do not exploit the fact they live with a leg ulcer. For the majority, they live quietly with the condition, concealing it from the public and their family. If anything, their ulcer is a constant reminder of their drug use and they are desperate for it to heal.

Scambler (2009) reviewed Goffman's concept of stigma which focused upon contemporary health issues and stigmatised conditions such as HIV and epilepsy as analysed in his earlier work. He proposed re-framing the notions of relations of stigma, signalling shame and relations of deviance. Stigma and deviance can be inscribed on individuals as well as embodied but they also form an oppressive paradigm. Scambler acknowledged that Goffman was aware of this but ahead of his time and concluded that stigmatisation can be steeped in exploitation, oppression and powerlessness. Scambler (2009) concluded that sociological studies of health–

related stigma can no longer be seen to neglect the social structural underpinnings of cultural norms and individual choice.

The stigma of illicit drug use and addiction may be motivated by inappropriate fears of contagion or danger, moral judgements about people who use drugs or other stigmatised practices or conditions. What motivates stigma and how it becomes manifest varies for different conditions. This variation also reflects social and cultural values and differences in health care and the attitudes and behaviours of health care clinicians who care for stigmatised populations (Weiss & Ramakrishna, 2006). There is no easy solution to challenging the problem of stigma associated with illicit drug use; health clinicians and social scientists must collaborate with the public to promote awareness and reintegration. More studies are needed around the magnitude and nature of stigma and need to address both its disease-specific and culture-specific aspects. One potential opportunity would be to explore the narrative or stories about the everyday lives of drug users living with leg ulceration. Through understanding the narrative one may be able to see the person behind the illness, therefore establish a better understanding of their condition.

## **2.6 Leg ulceration: impact on patient**

The 1990s observed major changes in the contribution nursing had towards improvements in leg ulcer service development, practice and research. Hyland et al. (1994) developed a questionnaire to establish the impact of leg ulceration on quality of life and found that patient management was more effective from the perspective of a bio-psychosocial interaction, inclusive of all aspects of a person's life. Charles (1995a) adopted a phenomenological approach for the investigation of the impact of leg ulceration on patients' quality of life using semi-structured interviews with the aim of exploring how the physical, psychological and social areas of the individual can be affected by chronic leg ulceration. The findings emphasised the helplessness experienced by patients suffering with a long term ulcer who often felt in a hopeless situation without control, and highlighted the need for therapeutic nursing care that treated the individual as well as the condition. Charles (1995b) highlighted that the majority of research relating to leg ulceration at that time had concentrated on the quantitative aspect in terms of healing rates, numbers treated and costs and that there was limited qualitative work in this area. In the last two decades there has been a steady increase in qualitative studies focusing particularly on the impact on leg ulceration on the whole person and their physical and psychosocial functioning; pain

remained a constant and dominant feature in the literature (Green et al., 2013) The importance of the “lived experience” and the impact of chronic leg ulceration on necessities such as footwear, clothing and self-image are also importantly represented. Madden (2015) conducted semi - structured interviews with 19 patients exploring the outcomes and impact of footwear, bandaging and hosiery in everyday life for leg and foot ulceration; interestingly six of these were IDUs however the study admitted that this group were overrepresented. There was also an incentive of £10 to take part which admittedly may have been an inducement to be involved. The study was relevant in addressing the practicalities of living with a leg ulceration however the narratives from the IDU population were purely functional and overall did not demonstrate the person. UK studies have formed an important part of this contribution to the literature.

Today in the field of leg ulcer care and wound management we appreciate that healing can mean different things to different people and for those living with a chronic leg ulcer, where healing may not be an option, other aspects of wound management such as managing pain, malodour and wound symptoms are just as important. Vascular surgeons are the main referral specialists that may review IDUs with leg ulcers in the acute and urgent setting. The focus for vascular surgeons in this particular patient cohort remains with acute vascular injuries and limb or life salvage interventions. This to some extent is short-sighted with this population, given that the aetiology of the injury and the addictive behaviour often coincide. Woodburn and Murie (1996) recognised that the role of the general and specialist vascular surgeon was limited at this time in the management of vascular complications relating to this patient group and admitted that surgery had little to contribute in the majority of vascular injuries caused by drug injection. Today surgeons and those working alongside the team are key people in reducing the potential harm caused by injecting such as abscesses, pseudoaneurysm and chronic leg ulcer management; the evidence demonstrated a gap between nursing and surgical care both in hospital and community when caring for this population. There are a small number of papers within the surgical literature that highlighted wound complications in the IDU population; however, there were few sweeping statements within the studies describing IDUs as interfering with their healing wounds and having poor compliance. The cases also mentioned the withdrawal of treatment as the final option for being non-compliant (Iyer et al., 2011; Iyer et al., 2012). It could be argued that this small body of evidence is mainly anecdotal but may have been responsible

in labelling IDUs with a “bad name” in terms of compliance and behaviour and ultimately this affected the way clinicians regarded this group of patients.

Quality of life continued to feature strongly in the literature relating to leg ulceration and to produce important findings on the impact of pain in chronic ulceration, however although one qualitative study had large samples of 156 participants most of the samples recruited were over retirement age with no deviation from what characterised the normal older adult leg ulcer population (Walters et al., 1999). Rich and McLachlan (2003) chose a descriptive phenomenology using semi-structured interviews to explore patients’ experiences of living with a leg ulcer; once again it revealed common themes to previous similar studies including the impact of pain on quality of life and support for the individual, social and family life. However, this was a small sample of eight patients again with an older mean age of 77 years which although valuable in content is not an inclusive representation of the leg ulcer patient population. Morgan et al. (2004) also used questionnaires to explore the associations between chronic venous ulceration on individual illness behaviour and social support networks with results confirming that venous ulcers impose considerable stress and demands on patients. However, the mean age of the 74 participants in the study was again older at 73.5 years with only 26 patients recruited younger than 70 which indicated that there were ulcerations in the younger generation however the study was not specific to the history of the younger population or how the ulceration occurred.

### **2.6.1 Leg ulcer care in the IDU population**

The literature presented here was concise and specific to the related topic however it was restricted in terms of quantity and variation in authors. There was a small body of evidence within the nursing literature, specific to tissue viability and leg ulcer care coming from case studies on the management of leg ulceration in IDUs. The papers are valuable as they demonstrated the real-life challenges clinicians faced when managing these patients such as their unique social and physical complications alongside their leg ulcer. They also confirmed the need for a greater intercollaborative working and skill sharing between specialists in primary and secondary care (Acton, 2008; Cook & Jordon, 2010; Wheatley, 2007). Wound case reports from Italian authors showed similarities in care and learning opportunities (Acquaro, 2012). Interestingly, a study in the USA showed that older IDUs with chronic wounds had potentially less risky wound care practices, better hygiene and

safer injection techniques compared to younger IDUs without wounds. It was also demonstrated that older IDUs with chronic wounds were more likely to engage with health care providers and to address long term health problems that may have been left untreated (Smith et al., 2014). My earlier work exploring services for IDUs in England highlighted the complexity of this patient group and their multifaceted health care needs. The work addressed the need to bridge the gap between the many services IDUs come into contact with and call for more research to address the lived experience of leg ulceration (Geraghty, 2012a). Clinically I have contributed to the literature in managing leg ulceration in the IDU population in emergency departments. This paper has attempted to provide clinicians with practical information on how to treat IDUs with focus on engagement and the establishment of effective therapeutic relationships (Geraghty, 2015a). It became apparent early on in the review that the voice and the personal narrative of the drug user living with a leg ulcer was absent in the current literature. The potential use of the narrative to explore the lived experience of this condition will be explored further through the work of authors that analysed this cohort of patients.

### **2.6.2 Authors in the field of IDUs with leg ulceration**

The national and international literature has reported on different realities worldwide by authors in America (Professor Barbara Pieper, Associate Dean, College of Nursing Detroit, USA), Scotland (Dr Alison Coull formerly Finnie, Lecturer in Nursing, Edinburgh Napier University, UK) and Canada (Assistant Professor Simon Palfreyman, Faculty of Nursing, University of Alberta, Canada previously Sheffield Teaching Hospital, UK). These authors have demonstrated an important contribution to the literature specific to leg ulcer care in the IDU population and associated health care needs of drug users.

Pieper has an extensive legacy in the leg ulcer literature and notable interest in the clinical care IDUs receive. Pieper (1996a) collected descriptive retrospective data from persons who had a history of heroin injecting and attended a wound care clinic for venous ulcer care; a tool was also developed to record demographic, health and illicit substance use from the participants that proved a great success in establishing the problem of leg ulcers in the IDU population within the literature. Pieper (1996b) further contribution to the literature was the recognition of major psychosocial implications of heroin and cocaine abuse; the author considered the development of a wound care service specific for persons with a history of injecting drug use. Pieper

and DiNardo (1998) explored the reasons for nonattendance for the treatment of venous ulcers in a wound clinic. Thirty-six patients with a venous leg ulcer and 115 people without leg ulcers responded to a survey that explored the reasons for missing clinic appointments. The sample which comprised of 36 people with venous ulcers found that 32 (89%) had a history of illicit injected drug use. The results for nonattendance at appointment do not differ to that often seen today in clinical practice. Lack of transport or inability to access, lack of money to fund and forgetting the appointment as well as the weather were all reasons given for nonattendance. Piper concluded that missing appointments does have a negative impact on wound healing and that examining reasons for nonattendance may help clinics look at options for improving attendance rates; persistence was also highlighted as an essential component of working with patients who miss appointments an attribute still required today when working with nonattenders. This was expanded further with Pieper et al. (2000) using questionnaires to collect data relating to health, substance misuse history and quality of life. The author addressed the topic of IDUs with leg ulceration which until now had been largely neglected in this population and called for IDUs to be included in psychosocial research with a view of investigating the impact of leg ulcers on their lives. Pieper and colleagues went on to explore other health related complaints associated with leg ulceration in the IDU population such as CVI and the risk of ulceration, the relation of ankle mobility and CVI in HIV-positive persons with and without a history of injecting drug use, and associated pain and function in IDUs with CVI and risk of falls among injecting drug users (Pieper & Templin, 2001; Pieper & Templin, 2003; Pieper et al., 2006; Pieper et al., 2007; Pieper et al., 2012). Pieper and Templin (2007) have added a scientific depth to the IDU leg ulcer literature in terms of the presentation of the pathophysiological changes that injecting drug use has on the venous system, skin muscle and the joints of the lower limb. This work has been further expanded to explore the impact of balance, and walking mobility for injecting drug users (Pieper et al., 2008a; Pieper et al., 2008b). In recent years Piper et al. (2009) and (2010) continued to expand and develop research relating to implications for injecting in the lower extremities and to the vascular health of drug users. There is a significant learning opportunity from the research that has been undertaken in the USA that could be replicated in the UK.

There has been a small body of research undertaken in Scotland, UK. Finnie and Nicolson (2002a, 2002b,) (Nicolson - Manager, Big Issue Health Project Glasgow) enriched the UK literature in relation to this topic and again highlighted the need for further research into the management of chronic wounds and the link IDUs have with

depression, low self – esteem and mental health problems therefore they required understanding and support. The Big Issue, founded in 1991 is a street newspaper, an award-winning publication that offers homeless people or those at risk of homelessness an opportunity to earn an income by selling the paper for a small percentage profit “offering a hand up, not a hand out” (Big Issue, 2017). Coull (formerly Finnie) had a particular interest in young injecting drug users in Glasgow, Scotland and published a recent prevalence study of skin problems and leg ulceration in a sample of two hundred participants between the ages of 21-44 years with 148 males and 52 females. Just under two thirds (n= 127) of the sample were currently injecting or had injected in the last six months; the remaining 73 had not injected in the previous six months. The methods involved a survey where data were collected using structured face-to-face interviews with a specifically designed questionnaire. The aim of the study was to identify the range and extent of skin problems inclusive of leg ulceration in a sample of IDUs. By categorising and defining skin lesions caused by injecting the study was able to quantify these within the sample. The findings revealed a high prevalence of leg ulceration in the sample, 15% of the sample population had experienced a chronic leg ulcer while seven per cent had an active ulcer at the time of interview (Coull et al., 2014).

Palfreyman et al. (2007) also contributed significantly to the literature at the time in relation to quality of life with IDU's using qualitative methods to explore the impact of venous leg ulcers on health-related quality of life in current and previous IDUs and the general population. Participants were recruited from community leg ulcer clinics in Northern England; altogether 19 participants were interviewed, a relatively small sample age ranges between 27-79 years. Of the 19 participants seven had a history of intravenous drug use with an average age of 32 years compared to 61 for those with no history of injecting. The findings of the interviews presented under the themes symptoms, attribution, social restriction and disempowerment. Pain was the main symptom that affected all the participants and the IDUs felt their quality of life was more affected than that of the general population in the experience of social isolation and the reluctance to access health care services because of fear or discrimination or a previous poor experience. Palfreyman, et al. (2010) conducted a systematic review of health-related quality of life instruments used for people with venous ulcers and found that people living with a venous leg ulcer did have a lower quality of life than the general population.

It appeared from this literature review that the papers specific to chronic venous ulceration amongst IDUs, although valuable, are only marginally represented by a

few authors. The research evidence available, covering the broader topics of chronic leg ulceration and attitudes and beliefs, can be drawn upon to strengthen the argument that this study proposal is both relevant and valuable and may complement the existing theoretical knowledge and build on existing qualitative studies by producing theory and recommendations that will benefit the population, clinicians, communities, organisations and fellow researchers. By exploring the experience of IDUs living with leg ulceration and having captured this unique insight this would help bridge some of the literature gap highlighted within clinical practice.

## **2.7 Conclusion of review**

The review has highlighted a clear division between the generalist health care and the psychosocial literature regarding leg ulcer care in the injecting drug user population. This gap in the evidence reflects a significant separation between the physical and psychological aspects in the provision of wound care for this group of people. As a result, the holistic clinical wound skills required for people who inject drugs living with leg ulceration are a miss in general practice, secondary care and for those working directly with IDUs. Overall, the generalist literature failed to address in full the broader health care needs of IDUs in the wound care and leg ulceration management. More specifically, the literature underlined a significant gap in the management of pain and associated behaviours of IDUs with leg ulceration in generalist settings and hospital care; furthermore, it showed the lack of academic curricula relating to this topic for nursing staff. This review demonstrated the independent growth and development of tissue viability services and specialist harm reduction services for PWID; however, it emphasised a failure as yet in the integration of these specialist areas.

The seminal work of Erving Goffman (1963) remained a cornerstone throughout the review and helped support the theoretical framework of exploring the concept of the stigma and spoiled identity through the narrative lens of IDUs living with leg ulceration. The purpose of referring to Goffman's pioneering work was the transferability and usability of his theory in everyday practice, across all disciplines of health and science. Goffman's pioneering studies on intricately complex phenomena proved to maintain intact purpose and relevance over 50 years later. Specifically, the ability to dismantle and reassemble the ideology of spoiled identity without disengaging from the norms and mundane of everyday life. The true value of his work can be embodied within the experience of IDUs living with leg ulceration by the ability to portray the complex face of stigma and identity in ordinary life. Goffman

exemplified the face of spoiled identity and stigma by looking to everyday bodily and psychosocial conflicts experienced by those who live with stigma.

The theoretical underpinning of the research question was influenced by Giddens (1991) theory of “duality of structure”. Fundamentally, this was a landmark in the original thinking behind exploring the experience of IDUs living with leg ulceration and focused on the philosophy of how the social world views people who have injected drug live and experience daily life with a leg ulceration. In summary, Giddens questioned whether it is the person or the social circumstances consisting of rules, regulations, boundaries that shape reality. The author concluded that both the person and the circumstances are intertwined. IDUs, by way of misbehaviour, actions and deviance from accepted rules, go against what is perceived as socially acceptable which in turn leads to misunderstanding, exclusion and marginalisation. Furthermore, this concept of misunderstanding and segregation affects ontological security, feelings of trust, place and person. The narrative of IDUs living with leg ulcerations has the potential to create a better understanding of this group of people; this could help bridge the social distance and restore ontological security.

The literature review concluded that there was insufficient evidence from studies undertaken exploring chronic leg ulceration in IDUs particularly in the UK and none that demonstrated their experience of daily life in their own words. Specific research was needed to explore the personal accounts and experiences of IDUs in the management of their ulcers on a day-to-day basis. The proposed study aimed to build on the limited existing work to increase knowledge of their experiences and to add to theory and understanding of what health services can do to support this marginalised population. This study was unique in that it provided IDUs with the tools with which to express their experience; firstly, in the form of a diary which allowed them freedom to express feelings and experiences of living with leg ulceration and then revisiting and exploring further this experience with semi-structured interviews. The literature review was a valuable platform from which to launch this study and provided powerful insight through narrative inquiry into the lives of PWID living with leg ulceration.

## **Chapter Three: Methodology**

### **3.0 Introduction**

This chapter will present in-depth explanation and justification for the methodologies used in this study with the discussion on the narrative approach in line with the overall aims of the design and research questions. This study utilised narrative inquiry as an approach to understand the world views of IDUs living with leg ulceration, drawing on a naturalistic paradigm. The naturalistic worldview is articulated in this study by the liberation of voice through interpretive naturalistic methods using diaries and semi-structured interviews that aspire to capture the lived experience. Each stage of the data collection process will be explained; emphasis was placed on the insider-outsider debate and the proximity of the researcher to the subject of enquiry. Following this, a comprehensive critical discussion on the ethical issues that were central to this study has been reported, highlighting the ethical theories and stance of the researcher. The chosen ethical approach was explored in relation to researching the experiences of IDUs. These elements of professionalism entangled within the methodological process will be unravelled to reveal the challenges, rewards and exclusive insight researchers with a background in the caring profession experience when undertaking research of this manner.

### **3.1 Naturalistic paradigm**

Scientific inquiry is based on theoretical perspectives and paradigms on which social scientists base assumptions; these applied theories help to shape questions on how the world is viewed (Bowling, 2002). A naturalistic paradigm was chosen to capture the subjective nature and multiple interpretations of reality as expressed by participants who were living with a leg ulcer. In this context as naturalistic researcher, I aimed to understand how IDUs constructed their own reality within their social world of addiction, recovery and wounded body (McInnes et al., 2017). When designing the underpinning methodological framework, the liberation of voice was considered central to the naturalistic position. The belief was that the best way to understand IDUs in their everyday life was to provide a means in which participants had freedom to express how they felt in their own words. Control would distort the inquiry process while a naturalist lens focused on an authentic lived experience in its natural environment (Miles et al., 2010). In contrast to the positivist paradigm, the naturalistic view observed and considered "...the inquirer and the object of inquiry interacted to influence one another; knower and known were inseparable" (Lincoln &

Guba, 1985, p. 37). Qualitative methodology is grounded in understanding the experience of people and seeks to explore the everyday occurrences as they happen in ordinary life (Marshall & Rossman, 2006). The qualitative process presented a means to capture the journey of the participants to gain unique insight to understand the processes that shaped how they lived with, and managed their leg ulcers. This design focused on the narrative of living with a leg ulcer; the wounded became the storyteller, portraying his or her personal story and giving voice to his or her body. Story-telling is a difficult and emotional journey when living with a disease and an addiction that have injured both the body and the inner voice. The concept of the wounded voice was eloquently explored in the work of Frank (1995) who emphasised the need for the wounded to become storytellers in order to regain their voice.

### **3.2 Narrative inquiry**

Narrative research, grounded in interpretive hermeneutics, aims to understand the human experience through the use of text. The assumption was that participants would portray their experience and life through an autobiographical process thus producing a story (Josselson, 2006). Narratives are stories that present the unfolding of events, human action or suffering from the perspective of an individual's experience (Muller, 1999). The narrative permits the presentation of experience in its true form, uniquely complex to the individual in all its richness (Webster & Mertova, 2007). Narrative inquiry offered a method of investigation that supported the aims of this study, which was fundamentally about experience, feelings, and emotions unfolding within the participant's daily journey with their leg ulceration. The study of narrative is the exploration of how humans experience the world in which the narrative is both the phenomenon and the method (Connelly & Clandinin, 1990).

Riessman and Quinney (2005) discussed the concept of narrative inquiry as cross-disciplinary; no longer isolated to one academic area, narrative inquiry has positively impacted on both medical and nursing clinical research. The focus on language may have some foundations in phenomenology; however, its application surpasses the lived experience with the central theme being the study of social interactions and relationships (Frank, 2000). Frank (2000) illustrated the narrative perspective in five points. Firstly, he differentiated between a story and a narrative; although these terms are often used interchangeably their meaning differs: a narrative is what underpins a story either through structure or analysis; people do not tell narratives,

they tell stories. Secondly, the telling of stories is the way in which people reiterate or confirm the story they wish to tell through sharing with the listener in a recursive way. Thirdly, storytelling can be a cathartic means of remoralisation and recuperation. Fourthly, stories may constitute valuable data for analysis; however, Frank (2000) emphasised the risk of reducing the story to a narrative means, missing the purpose behind the story. Lastly, those who tell stories relating to experience or illness wish to be heard and wish to establish a relationship with others who will answer their story's call. Frank (2000) believed that there is an ethical responsibility for those analysing stories to enter into the relationship of storytelling and to question how one can capture the essence of a story without first listening. The idea of capturing the stories of IDUs experience through diaries was to explore the concept of how "...we can live different forms of life within the same social world" (Frank, 2000, p. 361).

Frank (1998) also explored the professional use of narratives for listening to people's stories about ill health. Stories can reveal the impact and true meaning of the illness in the life of the sick. In order to facilitate storytelling there must be participation and desire from those who care to listen. Frank (1998) believed that when clinicians lack their own philosophical beliefs and values in caring for the sick, clinical care becomes uncertain at best and, at worst, evasive. The greatest gift clinicians can give to their patients is to "...appreciate them as the good stories they are" (Frank, 1998, p. 361). For the purpose of this design, my place was as listener to the stories told and shared, supporting and reassuring participants with their journey while valuing their contribution to the research.

Resistance remains on the validity and the need for stories in research, particularly nursing research, with evermore emphasis on RCTs to quantify results (Carson & Fairbairn, 2002a). However, not all results can or should be reduced to numbers; Carson and Fairbairn (2002a) considered storytelling to be central to exploring the experience of human lives, highlighting that nurses are often influenced by professional and personal values and morals. The authors (2002b) added that the use of stories for nursing research is powerful if nursing researchers wish to change the clinical world, the quality of patient care and capture the essence of patient experience. Carson (2001) explored the importance of narratives in medicine and education for ethical reflection. Stories are an important way for practitioners to reflect and learn from difficult clinical situations; by listening to patient's stories we can learn to value the patient's contribution to their care rather than relying on medical science alone. As Carson (2001) tells us "... narrative methods remind us that behind every practice, there is a person, waiting to be heard" (p. 202).

### 3.3 Research design and methods

In keeping with the naturalistic paradigm, the qualitative design embraced the use of diaries, interviews and narrative approaches. The purpose of using qualitative methodologies was to consider the personal journey of living with a leg ulcer, in an attempt to understand the complex social phenomenon of physically and psychologically wounded people with a background of injecting illicit substance. Furthermore, the aim was to investigate the emotional and practical impact of living with a leg ulcer on their daily life. The ultimate objective of this research was the development of concepts to help scientists and clinicians to understand the social phenomena of the wounded drug users, conveying meaning to the experiences and views of IDUs (Pope & Mays, 1995). The layout of the design was to facilitate the description and explanation of life events and experiences, yet never to predict them. This was central to the identity of the methodology: to collect and interpret the data as close to its source with minimal intrusion (Willig, 2001). Considering the complexity of this population, Silverman (2013) emphasised the strength of qualitative research in bridging the social distance between marginalised populations and science.

The concept of what makes people hard to reach and separate from conventional society is explored in Giddens' (1991) theory of structuration. Giddens questioned whether it is the person or the social circumstances surrounding that person that shape our social reality. He argued that, although people are not entirely unrestricted in their decisions and actions, they are the medium through which the social structure is reproduced leading to social change. In the case of drug users, they are often seen as victims of their own behaviour. The person and the circumstances are intertwined in what Giddens describes as duality of structure. At a basic level, this means that people, through their actions, make up society; yet are restricted by social structures. Giddens defined structures as consisting of rules, resources and human actions; this could be related to what is seen by society as acceptable moral action and structure. Drug use, addiction and the social consequences of what drug use entails goes against what is considered socially acceptable. This creates distance within society and creates misunderstanding often leading to exclusion and marginalisation.

This concept of misunderstanding or segregation may have an effect on ontological security. Giddens (1991) referred to ontological security as a sense of continuity, belonging and order to a person's encounters in life. Ontological security according

to Giddens had to do with feelings of trust in people, place and in routine. If drug users with leg ulcers feel excluded from what is considered conventional society, how can we as scientists and health care practitioners regain their lost security and trust? By bridging the social distance and by a deeper understanding of their true experience, we can empower and restore ontological security.

The richness of qualitative data is greatest when the subject of study cannot be controlled and is poorly defined (Black, 1994), as is the case with various hard to reach groups including people with a history of illicit drug use who have lived with an open wound on their leg. The intricacy of this cohort and the potential chaotic nature of the participants led to many challenges. This included engaging with the participants, maintaining momentum and being able to collect sufficient data. It was maintained that, although challenges were to be expected during the duration of the study, the overarching importance remained to expose a phenomenon that due to value-laden societal structures was largely suppressed and concealed. The chosen methodology aimed to convey a sense of sincerity that would encourage participants to uncover their experiences of living with a wound. Social research is about understanding people and the ways in which people act, interpret and understand the world around them. It captures what people see and understand about their circumstance, how this impacts on behaviour and interaction and, in turn, how actions are perceived by others (Wilkinson & Birmingham, 2003). This idea was pivotal to how the research question and the overarching design of this study were framed.

### **3.3.1 Research question**

**Question:** What are the experiences of injecting drug users living with leg ulceration?

### **3.3.2 Primary objective**

**Aims:**

1. To explore the experiences of IDUs attending leg ulcer clinics, from a narrative perspective.
2. To examine IDUs experiences of having leg ulceration and how this impacts on their quality of life and recovery from addiction.

3. To explore how clinicians / health professionals work with IDUs in leg ulcer clinics.
4. To explore what prompts IDUs to seek help for their leg ulcer care.
5. To explore IDUs route of access to leg ulcer clinics.

**Specific questions:**

1. How do IDUs describe their history and experience of developing and living with a drug induced venous leg ulcer?
2. How do they describe interactions with health care practitioners and services?
3. What are the implications on current clinical guidance and training for health care professionals who look after IDUs with leg ulceration?

The findings have the potential to raise important issues about the delivery of care and IDUs' service experience, eventually highlighting successes, challenges and possible failure of services.

### **3.4 Exploring the methodologies**

It was important to demonstrate the suitability of the chosen methodology to address the research questions, as this formed the basis of the study and supported the complex management of the data collection and analysis (Creswell 1998; Liamputtong et al. 1999). Different methodologies were considered for the design of this study. The selection criteria have been reported to highlight the appropriateness of the chosen methodological process in relation to the specificity of the research questions and of the analysed population. While reviewing the questions in line with the methodology, importance was placed on the most practical, efficient and unobtrusive means of collecting data from participants.

The literature review as a foundation for exploring effective ways to capture the experiences of IDUs, confirmed that a qualitative design was the most valuable means in which to gain a unique insight, understanding and critical reflection into the processes that shaped the social order of this phenomenon (Wilkinson & Birmingham, 2003). Creswell (1998) explored the process of a good qualitative study, depicting it as a complex process involving extended periods of fieldwork

collecting words and pictures, analysing data, focusing on participant's views while detailing the process using expressive and persuasive language. At the beginning of this proposal various methodologies were explored to establish whether they could effectively answer the above questions, the most relevant being observational studies and focus group work.

Silverman (2001) showed how observational studies have been fundamental in qualitative research in understanding other cultures and behaviours in many sensitive clinical areas such as observing HIV patients who attended a genitourinary clinic. I explored the process of observation in a small sample of smokers in the early phase of the Doctorate Programme and subsequently published my experience. This did influence my decision when considering the best way to explore experience and interaction of persons with a background in substance misuse (Geraghty, 2012b - Appendix 5). An observational approach to capture the experience and feelings of patients with leg ulceration at one point in time would not answer the questions pertinent to this study. The narrative approach in the context of this design is embedded within the experience, feelings and words of participants captured on paper and the interpretation of their lives as emerging from their stories.

Observing the population would not capture their experience or indeed their unique story and an observational design would not address the research questions and the overarching objectives. There were also a number of practical issues: observational methods would have raised some issues with the respondents in terms of viewing their wound-dressing changes in the community or clinic setting; this could have affected their behaviour around other participants and clinicians as there is always uncertainty surrounding the extent to which individuals modify their behaviour in the presence of the observer (Punch, 1993). Observing this group of people to explore their experience would mirror that of an ethnographic study and would have involved watching daily life of IDUs, behaviours, culture and patterns of activities. Although observing this population living with wounds would have proved an additional layer of exclusivity and insight into the life lived, for the purpose of this design it was confirmed impractical. There was the issue of safety to consider from the perspective of the researcher, in relation to the activity of the participants. There was also the element of intrusion this would have caused to participants' private space. From working with this population, I would consider this depth of inquiry outside the remit of this study although potentially it could be further explored in controlled circumstances, such as observing IDUs when they attend the leg ulcer clinic to have their dressing changed, or observing how IDUs manage their leg ulcer in between

dressings changes, if they are required to change their own bandage. Overall, observing daily life would involve close proximity to participants and the additional burden and potential risk to participants outweighed the benefits of this methodology.

On the contrary, the narrative approach, in the context of this study, seemed the most appropriate and pertinent design: the narrative theme is embedded within the experience, feelings and words of the participants, it is captured on paper and the interpretation of their lives emerges from their stories.

Focus groups were also contemplated; these are seen as a form of group in-depth interviewing, a way to establish group opinion, comparisons, similarities, successes and challenges in a facilitated manner. Yates (2004) described them as a fast and easy means to generate as much data and work in less time compared to in-depth interviews; however, focus groups require the researcher to be methodical in their approach and an organised commitment to time and place is expected on the part of participants. Although focus groups should not be dismissed completely in exploring the lives of this population, there were a number of practical considerations to facilitate a successful group-meeting of IDUs living with leg ulceration that this small-scale design was unable to meet. Assembling people whose lives can be unpredictable in a collective and systematic way was a disadvantage of this methodology. It would have meant gathering in an area that was convenient to all participants; given the three sites of recruitment, this would have proved not feasible and there would have been likely financial costs including room facilities and travel expenses to compensate. Facilitating people to voice their experience at one time was not seen as the most productive way to capture their individual experience and a number of problems were foreseen. The structure and regulation required to run the focus groups were outside the resource capacity of this study, alongside supporting individuals to voice their experience in an undiluted manner while directing the group as a whole. There were also a number of potential ethical dilemmas and safety issues which may have occurred: would participants be willing to disclose their wounds and the feelings that accompanied them to fellow participants; would this exacerbate feelings of vulnerability or the burden of living with the wound itself? The focus groups could have highlighted some useful collective information such as routines and rituals of dressing changes and self-management; however, it is unlikely to have provided the unique individual insight and liberation of voice, the focal point of this research. There were a number of key factors required in the development of a well led focus group which did not address the research question within this population. These included facilitating the arrangement and meeting a structured and sizeable group of homogenous participants in a skilful and permissive manner: a

challenge that was not possible within the resource constraints of this study (Krueger, 2006). In addition, it could be argued that the coincidence between the roles of researcher and moderator of the focus group could have unintentionally influenced the agenda, the content of the discussion evolved and, to some extent, the final outcome. There was also the matter of self-disclosure within the focus groups for participants with a history of illicit drug use; this could have proved difficult and burdensome when discussing living with a leg ulcer amongst other users (Morgan, 1996). Further limitations included potential links participants may have had with contributing participants including social relationships, their substance misuse and often their maintenance and recovery worker. By facilitating participants coming together to interact and discuss ideas may not have been the most constructive way to gain trust and insight into their individual experience as they may have felt unable to expose personal information or may have simply been embarrassed about their ulceration. These issues raised in their entirety excluded focus groups from the research methodology

### **3.5 Recruitment strategy**

Having worked with people with a background of illicit drug injecting, I had expected challenges with recruitment in terms of numbers, gaining access and establishing relationships with participants. One of the reasons the recruitment of participants was successful in this instance was the relationship and clinical knowledge I had already established in my clinical practice with this client group. At the time, I was one of a few specialist clinicians in London providing hands on expert leg ulcer care to clients with a background of illicit drug taking and this clinical backdrop facilitated direct contact between potential gatekeepers and participants. Recruiting people with a view to share their story in their own words, by means of the diary methodology, is an intimate request and there was an expected amount of exposure in terms of feelings and experiences. Establishing boundaries and developing trust between participants, as well as an open and negotiable relationship based on transparent communication, was essential throughout this process. Flexibility proved to be a key feature in the design of this study. Once the requirements of ethical approval had been established my approach to recruitment was to work openly with participants to capture their voice in an undiluted and outspoken manner, giving meaning and vigour to the words liberated by process of narrative inquiry.

### **3.5.1 Background: the sample**

A purposeful approach was utilised whereby the sample was identified on the basis of the characteristics of the given population: participants with a background of injecting drugs and living with leg ulceration, willing to share their daily lived experience. The identification of the sample and the recruitment process required a collaborative style as participants were considered hard to reach; I relied on the relationship with the gatekeepers and their own professional judgement in selection and informing participants about the study. Interaction and knowing the population was key to achieving a successful sample and emergent design (Lincoln & Guba, 1985).

The population was geographically positioned in North London; leg ulcer services within this region of London were sparse, with only a few general leg ulcer clinics providing wound care for this clientele. The sample was selected over three leg ulcer clinics: one hospital-based clinic and two community services. One of the community services was an established UK charity and social enterprise delivering healthcare for clients with mental health problems, substance misuse and employment issues. Snowball sampling via the gatekeepers along with word of mouth of the design facilitated a relatively straightforward recruitment strategy.

In total 12 participants were originally recruited, three women and nine men all over the age of 18 years with a median age of 52 years (ranging between 35 and 62 years). Two of the participants, aged 61 and 62 years, were married. All of the participants considered for the study were positioned easily into the recruitment criteria. There were no apparent participant's deviant within this cohort. The participants recruited were not in the acute phase of their addiction and the majority were using some form of maintenance therapy. Ensuring participants were at a stable point in their illness and/or recovery with the added support of gatekeepers reduced the likelihood of non-concordance with the design and also protected those who may have not been ready to participate.

Two of the male participants successfully recruited onto the study did not engage after the initial meeting and consent to take part in the four-week diary recording. They were contacted on two occasions with no result. For reasons unknown they ceased to reengage further with the study.

The sampling frame reflected the naturalistic qualitative approach of the design. The process of selecting suitable people for the study was at points difficult, particularly as the phenomena under investigation was a sensitive topic and there was the

potential for participants to conceal their activities. In the case of IDUs with leg ulcers, there was also the possibility that the less visible the area of interest or complaint, the harder it would be to sample (Lee, 1993). The population of IDUs with open wounds is considered both sensitive and deviant. The world of IDUs with leg ulcers is concealed from conventional society and healthcare for those who do not come into contact with this clientele. Gaining access to this specific NHS research group was challenging, given the numerous ethical obstacles in place to safeguard this vulnerable population. Qualitative sampling in this instance was considered the most appropriate method being intrinsically naturalistic: it took place in the clinic where participants had their leg ulcer dressed and included the home and everyday space where participants completed their diary.

Recruitment of vulnerable or marginal populations can be seen as a major barrier to research and requires extensive planning, time and effort to succeed. Singh and Keenan (2010) highlighted how ethical committees require extra caution when approaching vulnerable groups. On one hand, there was a benefit to knowing the target group, as this could provide a direct route of access. On the other, as an insider researcher I was aware of my dual roles in this case as both investigator and clinician with the potential conflict of interest. There were clear boundaries established within this design through the process of recruitment and consent. A key requisite of the recruitment process for this design was the establishment of gatekeepers, key clinicians who were aware of the participants' inclusion criteria for the study and who could facilitate access to the sample and advise on how best to approach patients (Barbour, 2010).

### **3.5.2 Gatekeepers**

The gatekeepers appointed were all specialist nurses working in the field of leg ulcer care who attended to patients with a history of injecting illicit substances in the lower limbs. As clinical lead in the field of leg ulcer care with a specific clinical interest in this group of patients, I already had connections with gatekeepers. The appointed gatekeepers were keen to support the aims of the study and expressed a desire to develop leg ulcer services outside that of the general population and to support clinicians in working with this clientele. Once the gatekeepers had been briefed on the study and inclusion and exclusion criteria, the identity and communication of potential participants was productive and timely.

Sutton et al. (2003) discussed the role of gatekeepers in recruiting vulnerable

populations and potential influence on patient choice and participation in research. As nurse lead for leg ulcer care within a large NHS organisation and a visiting clinician to outreach services for marginalised clientele, I had the privilege to voice the enthusiasm of many health care practitioners seeking, over the years, to investigate the experience of patients with leg ulceration and a history of substance misuse. Clinically, there was awareness of the challenges with delivering leg ulcer care for IDUs and one of the motives for undertaking this study was obtaining direct clinical feedback from patients and clinicians in this area of research requiring clinical insight into this population. In fact, there were no barriers to identifying participants for this design; having an established leg ulcer care service and the enthusiasm of the clinicians working with this population facilitated the identification of gatekeepers and the recruitment of suitable participants.

### **3.5.3 Inclusion and exclusion criteria**

Developing a robust framework was essential to ensure a correct process of selection ensuring to capture all relevant characteristics of the chosen sample and to exclude the confounding factors.

The study aimed to recruit a maximum of 15 current or ex injecting drug users with current or previous leg ulceration within an inpatient and outpatient leg ulcer setting, including wound dressing clinics. This was an ambitious target as clinically I was aware that the regular numbers of IDUs attending leg ulcer clinics varied on all sites. The sample aimed to include male and female adults aged over 18 years with a maximum age of 70 years of age. In my clinical practice presentation of IDUs with leg ulceration was between the second and sixth decade of age; the study confirmed this presentation. There was potential to recruit from general acute, and community settings and a non-NHS clinical facility to provide a diverse range of clients with a history of substance misuse. The aim of the inclusion criteria was to facilitate the complete recruitment of all potential candidates within the resources of the study and to safeguard this vulnerable population.

Language and literacy were considered as inclusion criteria. It was not within the scope of this design to recruit participants who were not fluent in the English language. For the purpose of this study participants must have been able to read and write in order to complete their diary entries. Involving fluent English-speaking participants was important to ensure informed and continuous consent; there was also a lack of funding for interpreters. Out of the 10 participants who completed the

design seven were originally born in the UK. The remaining three participants were born outside the UK; one from Europe, South America and South Africa. Four of the ten participants spoke English fluently as their second language.

The inclusion of adults with capacity and with no acute episode or on-going treatment for psychosis or severe depression was included in the framework. The exclusion criteria included visually and / or hearing impaired people in terms of inability to write the diaries or partake in the oral interviews. The process of recruitment and consent were key ethical elements with the research application to protect the participants' choice and to reduce the risk of potential coercion.

### **3.5.4 Recruitment and consent**

Potential participants were first approached by the nurse providing their leg ulcer care and were informed about the study. Once initial interest in recruitment had taken place via the clinician, I was contacted and met with the participant in the clinical setting where they had their leg ulcer dressed and participants were invited to take part in the study. Invitation letters were addressed to gatekeepers and participants (Appendix 6). A Participant Information Sheet (PIS) was also designed with initial feedback from the Patient Involvement Group at the University of Hertfordshire and provided to each potential recruit (Appendix 7).

Participants had one week to read the leaflet and consider if they wished to take part in the study and to consult with clinicians, friends and family about their participation. All the participants were known at some point in my clinical role and many were still under the care of the specialist leg ulcer service provided by my clinical department. Potential participants were assured that there was no obligation to take part in the study and that they could withdraw at any time during the project, being reassured that this would not affect the ongoing or future care they may have had with me or their gatekeeper in a clinical capacity.

After this time, I requested permission to contact participants to establish if they wished to take part in the study and to formalise a meeting for consent and interview. Due to the potential chaotic nature of this population it was necessary to be responsible for following up with participant recruitment. When contact was successful, a further appointment was scheduled within the clinical area for formal consent to be obtained. The participants were also asked if their General Practitioner (GP) could be informed of their recruitment, and, if agreed, the GP was informed in writing about their participation (Appendix 8).

From the initial meeting, all participants expressed an interest in taking part and share their story; some asked questions around why the research was being conducted and how it would help others. All of the potential recruits emphasised the importance of the study in highlighting the difficulties in accessing leg ulcer care. They were all positive about the research, considered it valuable and wanted to play their part.

The timeline for each individual dataset was as follows: an introductory meeting was arranged to introduce myself in the role as nurse researcher; in this setting the design and purpose of the study were thoroughly explained and the PIS provided. One week was then allowed for the candidate to reflect and a second meeting arranged at their local recruitment site with a view to sign and informed consent to enter the study; at this point the diary pack was given.

The participants were required to write the diaries for four consecutive weeks. The diaries were then collected within two weeks after completion. Following this the diaries were read in brief and analysis took place over a week time; further contact was then made to arrange the interview. Overall from start to finish the timeline of the full individual data collection set ranged from a period of eight - nine weeks. Often there was more than one participant completing their diary at the same time with scheduled interviews back to back. The study required careful organisation of dates and schedules around recruitment, diary collection and interview meeting to ensure the process ran to course. In total complete data collection took over 12 months from start to finish, this included transcribing of the diaries and interviews. The structure of the diary design for this study was unsolicited and semi-structured with emphasis on the participants own method to record when, where and how they deemed appropriate.

As chief investigator, I was responsible for obtaining informed consent from participants. This was an essential element of the study given the potential emotional burden to participants and the vulnerability of the group. Each participant was assessed for their mental capacity to make informed decisions regarding recruitment and participation in the study, in line with the Mental Capacity Act Code of Practice (2005). It was assumed that participants had capacity unless cause was given to think otherwise. All participants were able to make the decision about their involvement in the study to explore their experience of living with a leg ulcer. They understood the information leaflet that was provided and were able to ask questions about the study; these were answered. They proved to have retained the information presented within the PIS a week after when consent for participation was requested.

They were able to communicate their decision to take part in the study throughout the data collection process and on completion of the study (National Care Association, 2009).

Informed consent was continuously negotiated throughout the study and every effort was made to ensure participants understood what was being asked of them. Participants were aware of the risks and benefits of the study and the right to withdraw at any time without consequence. Participants were assured of anonymity throughout the study and the extent to which confidentiality would be maintained. Participants were also made aware of the potential uses of the data and how it would be stored and disseminated (Corti et al., 2000).

### **3.6 The insider-outsider debate**

The emic-etic standpoint of nurse-researcher was carefully considered from the initial planning and in the design of the study. There were a number of potential biases that could have influenced the research project; none more apparent than the fact that I, in my clinical role of specialist nurse, had treated the participants as patients. The possible impact of coercion also influenced my thinking and the design strategy addressing the questions on how to minimise the potential pressure on participants or what could be seen as intimidation, ensuring participants felt safe and in control of their own story. The development and maintenance of trustful relationships between all parties involved in this study proved to be the correct approach.

The role of gatekeepers was central to recruitment and establishing the initial distance required for me to then introduce myself in my new role as researcher. Without my relationship with the gatekeepers, which was again built on trust and confidence, the gatekeepers may not have facilitated recruitment so willingly. Their duty was to the patient, yet our clinical relationship, having worked and collaborated before had cemented the trust that this work was to liberate the voice of those who we understood in practice to be overlooked. The engagement with gatekeepers to explore this particular population would not have been possible if they had not already known that I upheld the fundamental ethical principles of beneficence, non-maleficence, respect for autonomy and justice: a moral commitment to protect and uphold the ethical standards of clinical practice (Gillon, 2015). In the real clinical work the gatekeepers trusted me and knew I respected and safeguarded the participants in my clinical role therefore trusted that I would do the same in my researcher capacity. Participants also engaged easily with the design and with my new role: they were proud and felt empowered that the person they trusted to care for their physical

body and wounds was now embarking on an exploration of their daily life through their story. I refer back to the relationship between nurse and patient, participant and researcher. The separation and respect for the two roles was grounded in the integrity of the nurse-researcher, the value of the data had to be true to what the relationship represented: engagement, self-disclosure and trust.

As lead nurse, having worked with diverse patient groups over many years, I have experienced the intuitive relationship that exists between the nurse and the patient. People who are hurt or “wounded” either physically or emotionally are remarkably perceptive to those who care for them and their general surroundings. There is an unspoken relationship between the nurse and patient, one that respects, listens and attempts to see beyond the physical constraints of illness or pain.

This intuitive perception is particularly developed in patients with a history of substance misuse who live with chronic leg ulceration; it is a protective characteristic which is amplified in the relationship between patient and clinician; I refer to it as “survival instinct”. This is a protective mechanism, a shield against body language spoken and unspoken stigma and prejudice. These individuals are incredibly resilient having had to overcome extreme personal difficulties yet solitary embracing the struggles of ordinary life even in their time of sickness. Establishing a relationship of trust, respect and empathy is of the utmost importance.

Gair (2012) discussed the importance of empathy as a key ingredient in understanding the lived experience of another with the discernible quest of hearing, feeling and valuing stories. Thomas et al. (2000) added that involvement as an insider and increased trust support the foundation of this design; to explore an individual’s life experience there must be respect, trust and commitment to become part of the journey and experience. In some respects, the study becomes another chapter in the story, one that participants can reflect on after the research finishes.

It is argued that, without this insight and considerate approach, I may have been unable to gain access and recruit participants and potentially collect the data required. The skill of nursing has provided me with the tools to manage the emotional weight of living with the stories of the participants. It is considered a fair cost to be allowed into the lives of this vulnerable group. On the other hand, an inside perspective may have led to preconceptions and a closed mind which may have prevented the generation of new knowledge and an open view of participants’ experience (Galvin & Holloway, 2017). Such criticism was overcome by adopting diaries as primary data collection tools, leaving full control of data contribution to

participants. This minimised the risk of selection bias by reducing any potential distortion. The emic-etic approach proved to be a complementary feature of this study; often academics and scientists wish to study closer populations that are difficult to understand, recruit and research. As nurse-researcher working on the frontline with these people, it was an opportunity to apply my skills in a research capacity. My clinical background was crucial in every stage of the study, from the design to ethical approval, to the data collection and analysis. A critical discussion on the ethical processes considered for this study and the current ethical stance of the researcher are now reported. The chosen ethical approach will be explored in relation to researching the experiences of IDUs.

## **3.7 Ethics**

### **3.7.1 Ethical application and approval**

Ethical approval was obtained from the Health Research Authority, National Research Ethics Service (NRES) Committee London in February 2014; REC reference: 14/LO/0086. Protocol number: HSK/PG/NHS/00140. Research governance approval (R&D) was obtained in March 2014 and access to NHS patients was granted from two NHS organisations and one private provider of substance misuse service in England and Wales.

One of the challenges faced within the process of this design was the lengthy completion of the Integrated Research Application System (IRAS) form. It took over 12 months to successfully complete and submit to the ethics committee. The form addressed every possible ethical consideration for the design specific to involving vulnerable NHS people. The time dedicated to the completion of the application was also used to develop networks with clinicians who had been working with IDUs in order to develop an understanding of practical measures regarding sampling and recruitment. Robinson et al. (2006) pointed out that traditional sampling methods for recruiting marginalised populations are often challenging or unsuccessful when the population of interest has stigmatised behaviours or a history of substance misuse, with IDUs being one such population. For this reason, exploring relationships and establishing trust was time wisely spent. I worked with the IRAS application addressing key ethical considerations such as informed consent, confidentiality and anonymity, the potential risks and benefits of the design and the reporting of poor practice.

There were many ethical dilemmas and practicalities considered for this study: the impact on both the researcher and the participants and the importance of anonymity of all involved parties in the research. The proposal was rigorous before the ethics committee. A constructive ethics meeting was held, with welcomed discussion on important matters, including the inclusion and exclusion criteria and practicalities of meeting with participants and travel arrangements. One of the issues raised was the difficulty for participants to afford the travel expenses in order to attend the interview. This was solved by the interviews taking place on the same date as the clinic visit or dressing change. The other query related to the exclusion of participants without fluency in the English language. The ethics committee also challenged the difficulty of engaging this group of patients, so often considered chaotic and non-reliable in their health care appointment attendance. This was a welcomed enquiry and one of

the motives for undertaking the study. The response to the committee challenged the preconception of clinicians having problems with engagement and retaining IDUs patients, showing how the clinics run by my team were instead fully attended. The feedback from the committee was positive and overall, they welcomed the study and the potential benefits to clinical practice. As the journey of recruitment and data collection began, the researcher presents a critical reflection of the ethical theories and current stance that helped shape this design.

### **3.7.2 Professional research ethics**

Qualitative research presents a range of ethical challenges that are unique to the study of human beings, with qualitative researchers drawing from various disciplines, both academic and practice based. Asking participants to expose their feelings may leave them in a vulnerable position and it is essential to ensure rights, privacy and confidentiality of the participant are protected while obtaining data and throughout the study process (Bassett, 2004). My role in the study and my professional background in nursing is a prime example of a practice discipline where the potential for conflict may arise between the role of the researcher and the professional obligation of the nurse (Eide & Kahn, 2008). There was the potential that a professional background and my clinical relationship with IDUs and their leg ulcer management may conflict with this study; however, without this relationship it may have proved difficult to gain access to the recruitment site, gatekeepers and sample. The involvement in the clinical management of their leg ulceration allowed me to establish trust with participants. The IDU population have been described as hard to reach due to their resistance in engaging with treatment services.

Respectful treatment of service users and the establishment of trust with partnerships is key to engaging with groups that are marginalised from mainstream health services (Flanagan & Hancock, 2010). Riley and Hawe (2005, p. 226) added that as we attempt "...to see the world through the eyes of others..." creating the appropriate research conditions for collecting data about experience is paramount otherwise participants may share only part of their story, what they think the researcher wants to hear or indeed nothing at all. I was aware of the potential bias within the study and the difficulties with recruitment and management of sensitive data; however, those should not have taken precedence over participants' rights and wellbeing (Parahoo, 2006).

Although the inclusion of vulnerable populations in research can be complex and ethically challenging, it is necessary to highlight participants whose views and experiences may otherwise remain invisible (Royal College of Nursing, 2004). Clandinin et al. (2010) emphasised the role of the researcher in narrative inquiry as being part of the phenomenon and interwoven in the stories of participants: as we attempt to study the lives of others we become part of their life as they do of ours. Therefore, while exploring the lives of IDUs it was important that clear boundaries were set to define the researcher-participant relationship, so as to protect the interest of the researcher while continuing to support the participant. I adopted a reflexive approach throughout the study to explore the researcher-participant relationship, developing critical awareness of myself (Finlay & Gough, 2003).

Furthermore, as we research the personal experience of others we assume responsibility to our participants and how our research narratives shape their lives. It was assumed at the onset of the study that as researcher I would not have had any clinical input with the participant in terms of their leg ulcer while in my research capacity. However, the ethical codes and principles that form the cornerstone of the nursing role cannot be overlooked within the contact that was made with participants throughout the study. Ultimately, these core values of care have shaped my way of thinking and reflected in the ethical stance within this study, with the primary responsibility being to uphold the tradition of nursing practice in which the honest nurse is the virtuous nurse. The moral agreement for the nurse is to care for the vulnerable, marginalised and dependent. Nurses have an obligation to submit oneself to the service of people even those who are strangers and those with challenging behaviours (Bradshaw, 1999). Nurses are in a prime position to undertake valuable qualitative research as we work on the frontline of healthcare and are exposed to the feelings and experience of patients. It was important for me to empower nurse professionals and other health carers to embark on their own research journey exploring patient stories of living with illness.

### **3.7.3 Ethical theories and virtue ethics**

The concept of ethical behaviour in general research, as with nursing research, is concerned with the understanding of key moral principles and perspectives of proper conduct and demands that researchers engage with what is morally right or wrong (Israel & Hay, 2006). The decisions and issues encountered in the planning stage of the design and those that were considered emerging, as the exploration of IDUs

experience unfolded, were influenced by several regulatory issues: the researcher's standards and guidelines within the research faculty, professional regulation by the Nursing and Midwifery Council, Code of Conduct (2008) and my own ethical and moral outlook. In order to identify the most appropriate ethical stance and its potential impact on this study, it was necessary to explore a range of ethical approaches and existing frameworks. This provided a means of understanding and comparing existing theories with my own ethical stance and moral principles (Wiles, 2013).

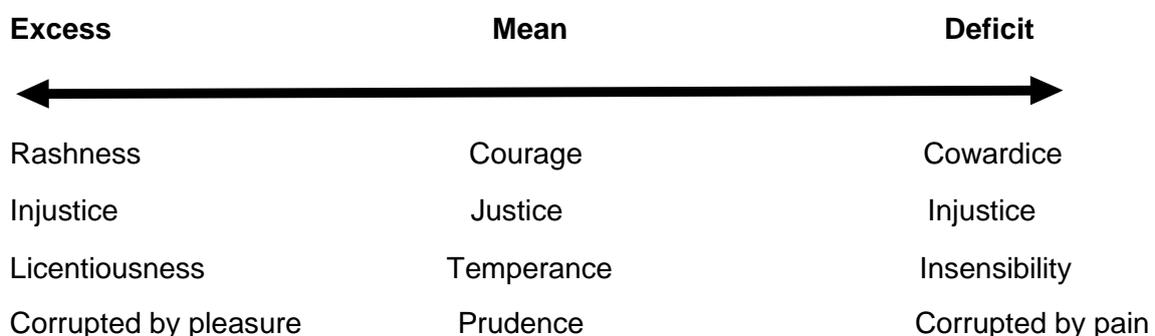
The nursing and medical field is dominated by three major ethical theories consequentialism, deontology and virtue-based ethics. The paradigm case of consequentialism is utilitarianism: the consequences of an act, not the act itself, determines the moral worth of the act; the action is considered good if the results are equally as good or of benefit (Oliver, 2003). Deontology, meaning the study of duty, is central to the theme that a moral person will always be dutiful without exception whatever the outcome. A deontologist would argue that certain obligations or rules are good in themselves regardless of the outcome and although it is sensible to consider the consequences of an action, ultimately duty is of utmost importance (Seedhouse, 2008). The ethical theory of virtue is often proposed as an alternative stance in health-care ethics where, unlike consequentialism and deontology which focus on action guidelines and consequences, the concept of virtue focuses on character and moral integrity (Allmark, 2012). Taylor (2013) highlighted that in the real world of clinical practice most clinicians find that all three perspectives although different have their place and offer useful insights depending on the clinical scenario and in some instances may be complementary.

Modern philosophy is witnessing the re-emerge of an ancient ethical philosophy which recognised the sensitivity to circumstance and rightly focuses on the virtues, character and traits of the person who acts, rather than the activity itself (Schmidt, 2013). As discussed by Brody (1988), virtue ethics can be explored using three, non-exclusive, perspectives: in the first instance virtue is described as a characteristic or attribute of the individual, the desire or inclination to act with integrity; for example, the researcher has a desire to do good. The second defines virtue not by the individual's character but through their actions, thus echoing the agent's moral instinct. The third perspective also involves performance but not through actions of moral attributes. This stance is portrayed as the ability of the person to achieve the moral obligations defined in their role. Brody (1988) gave the example of the nurse who works with the homeless and explained that fulfilling

private dedication does not constitute virtue; rather it is the fulfilment of a professional obligation and the role as the nurse that establishes virtue within this instance. Bradshaw (1999) described that virtues are required to care: loyalty and respect, benevolence, patience as well as compassion, dedication and humility. These virtues are embodied in universal moral principles and do not simply derive from feelings or attitudes.

Within modern research ethics certain groups of people are presumed to be more vulnerable than others given their dependent status or incapacity and require ongoing protection by law and regulation (Levine et al., 2004). The ethical stance of virtue which is embedded within my own nursing experience and practice; it has provided the moral conditions of trust and respect on which this study was based. If we act honourably and honestly, our participants may trust us to expose and recognise their vulnerability and their needs; as a result, they may be more willing to participate openly and fully to their journey within the study (Israel & Hay, 2006). Allmark (2013) discussed a criticism of virtue ethics in that the concept of fixed characteristics may not always be appropriate or true to form in an ever-changing environment.

Virtuous ethics prompts a habituated act and feeling, a state of being and doing, acquired human qualities developed with life experience. Aristotle's *Doctrine of Nicomachean Ethics, Books II–V*, described virtues to be habits learnt through experience and good character, by seeking the middle way and not the extremes of action and feeling. Unlike utilitarianism where the greatest good is often based on outcomes, seeking virtue endeavours to provide goodness for the individual (Harrison & Rooney, 2012). Aristotle's Virtues and the Doctrine of the Mean are presented in Figure 1.



*Figure 1: Aristotle's Virtues and the Doctrine of the Mean (Harrison & Rooney, 2012).*

The ethical stance I adopted in this study was true to the theory of virtue ethics. The challenges, successes and outcomes of this design did not take precedence over the moral obligation to protect participants, acting at all times with fairness and honesty in the portrayal of their voice. I had an acute awareness of the ethical principles relating to caring for the sick and advocating for the vulnerable as I continued to work in my clinical role throughout the study and continue to do so. The process of reflection and reflexivity with this study strengthened the ethical heart of the design by the sharing of story and experience. This was an opportunity to be invited into the lives and the past of some of healthcare's most private population. Applying the ethical principles to explore the experiences of IDUs living with leg ulceration involved using interpretive naturalistic methods of diaries and semi-structured interviews which will now be presented.

### **3.8 Data collection**

#### **3.8.1 Diaries**

The overarching means of data collection for this design involved diaries and semi-structured interviews. To date, diaries have been relatively overlooked as a social science research method particularly within the field of health research. However, diaries form a valuable part of the research process in which participants are actively involved in both recording and reflecting on their own behaviours and the goings on around them (Milligan et al., 2005). The diary-based study can be used to investigate a range of subjective phenomena allowing access to everyday behaviours, experiences and feelings in a relatively inconspicuous manner (Symon, 2004). There has been a great variation in the format and implementation of diaries written for research use and these reflective sources constitute an insight into the human lived experience (van Manen, 1990).

Based on their methodological use, diaries can be divided into different groups: diaries used as a primary method of data collection or a combined method of diaries and interviews; the latter was the preferred technique adopted in this study. Diaries represent a particular moment in time, whether recollecting on the past or writing in the present, and explore private expressions of emotion and allow participants to vent their feelings and experiences (Theodosius, 2008). Jones (2000) explored the differences between solicited and unsolicited diaries; solicited diaries are externally structured into time, events, people and places of interest while unsolicited diaries are more of a spontaneous nature with everyday life experiences being recorded.

The structure of the diary design for this study was unsolicited and semi-structured with emphasis on the participants own method to record when, where and how they deemed appropriate.

The chosen sample of ten participants with a history of injecting drug use living with leg ulceration proved to be sufficient in terms of successfully capturing and portraying the lived experience by process of narrative inquiry. All the participants met the inclusion criteria in line with strictly regulated NHS ethic protocols; despite the apparently relatively small number of participants, the sample represents an extremely heterogeneous and diverse group of people adding unique value to the whole collected dataset of diaries and interviews: the participants were recruited across three geographically separate sites; the group comprised of three women and nine men; they depicted different generations of IDUs with an age spanning between 35 years to 62 years, two of the participants aged 61 and 62 years were married and the youngest IDU of 35 years was married with a young child. Their cultural and socio-economic background was extremely different; nine of the participants were born in Britain, of those nine, eight were white British with one participant of British, Asian ethnicity. The remaining three participants had lived in the UK for many years and were born in the continents of Africa, South America and Southern Europe. This ethnic diversity reflects the demographic population of London at this point in time.

They all fluently spoke and wrote English, as per inclusion criteria, and at one point all the participants had worked in the UK in a permanent job. At the time of data collection one of the ten participants were in active employment, the remaining nine were unemployed. Data saturation was achieved by full completion of the personal stories using two separate means of narrative. The stories were seen as complete in themselves in that the participants chose opening to convey their story through this means. Narrative inquiry is not simply defined by the themes that arise in the stories captured; the true value of the personal story is in the interpretation which for this study was firstly through the person biography of participants then shared with the nurse-researcher.

### **3.8.2 Discussion of methodological diary literature**

The purpose behind the chosen methodology of semi-structured diaries was to allow participants to reflect and record behaviours, thoughts and experiences related to their leg ulceration and the treatment they received close to where the care occurred (Verbrugge, 1980). It was thought this may have proved challenging for some IDUs as the journey experienced in regards to leg ulcer care may not have always be clear due to the likelihood of multiple different experiences with clinicians in various

settings over time. However, as the data will demonstrate, the diaries and story were not only well defined but articulated and purposeful. It may also have been difficult for the participants to complete their diary due to the long term effects of substance misuse on memory and cognitive impairment that may have caused anxiety and confusion (Bonomo & Proimos, 2005; Crawford et al., 2003; Gossop & Moos, 2008). This showed not to be problematic and participants recorded past events clearly and with great passion. In some cases, the use of diaries helped to minimise recall errors, to reduce the possibility of memory lapses and proved to be a user-friendly and practical method of collecting data (Ross et al., 1994). Despite the above challenges that will be discussed later in detail, the proposed diaries would present important symbolic accounts in the wider context of what people have and/or are experiencing in the routine habits such as with living with their chronic leg ulceration. In addition to this the formal semantic structure used to describe their experience will also be considered (Kerr et al., 2011).

In terms of structuring the diaries for the purpose of this methodology, diary entries were encouraged from both a retrospective and prospective point of view to add weight and validity to the overall data collection and analysis. Corti et al. (1990) used diaries to measure the consumption of alcohol in women living in Perth Australia using both retrospective and prospective alcohol consumption diaries. The study highlighted that, although retrospective diaries are said to be less intrusive than a prospective diary, the inability of respondents to accurately remember the amount of alcohol consumed over the past week may have resulted in respondents under-reporting the amount taken; this may have also been the case with our participants regarding illicit substance misuse. On the other hand, as with the above study prospective diaries can provide a more accurate account of alcohol consumption, however the reactive and intrusive nature may influence behaviour.

Using suggestions from Boserman (2009), who explored the use of diaries with cannabis users the diaries had basic instructions on how and what to record identified within the first two pages and front cover of the paper diary (Appendix 9). It could be argued whether the participants should have been encouraged to write in the third person, therefore creating an emotional distance between the person and emotions, thus allowing disclosure. However, for this design the main purpose of the diaries was to encourage participants to write in whatever form they thought meaningful; there was no right or wrong way to record as with keeping a personal diary. Other areas that were encouraged within the diaries were creative forms of expression such as drawings and poems that may have related to the leg ulcer journey and experience. For example, if the participants wished to draw an image of

how a certain experience related to their leg ulceration or made them feel at a particular time then this was encouraged, even if using a substance. Diaries have been used as a means of expression, insight and therapy in addiction and mental health along with illustrations to depict feelings and experience (Baker, 2010; Sixx, 2007).

Välämäki et al. (2007) discussed the methodological issues in the use of diaries as primary data in a study of family caregivers of people with Alzheimer's disease, one of the research questions asked from this paper was: "What are the benefits and limitations related to the use of diaries in nursing research?" The paper explored the contribution diaries gave to the qualitative methodology in the richness and unique personal insight into participants' lives. The findings suggested that diaries were suitable for collecting data dealing with long-term illnesses or major changes in life which is consistent with the chronic condition of leg ulceration in injecting drug users. The paper did highlight challenges with the use of diaries by clarifying questions if a certain topic was unclear or interesting or identifying possible contradictory comments on a given topic in which the researcher must draw conclusion on the basis of the text as a whole. Stephenson et al. (1997) examined the relationship between the linguistic content of diaries and progress in treatment of 16 patients receiving treatment for drug, alcohol and food addictions in a residential centre in the UK over a three-month period. During the course of the study permission to read the diaries was obtained individually and the purpose of the research was explained again in group sessions. Three forms of socio-linguistic inquiry were employed: narrative characterisation, evaluative statement coding and computer analysis of word strategies. The results of these analyses were consistent with the view that personal diaries can reflect both positive and negative attitudes in patients and may be used to evaluate progress on an ongoing basis while contributing to the analysis of significant changes acquired through specific treatment regimes. However, the study recognised that the numbers were small and concluded that larger samples in a range of residential, community and self-help settings were needed for future studies.

Furness and Garrud (2010) conducted a qualitative diary study to gather accounts from five facial cancer surgery patients; participants were asked to record experiences, thoughts and feelings. One of the positive reports from this study was that participants enjoyed keeping a record in the diaries and recognised the valuable experience gained from the study while at the same time hoping the study would benefit others from hearing their stories. The diaries helped to present a picture of the impact of experiences in different areas of life, facilitating profound understanding

and effective intervention by practitioners. Overall, the study showed the rich data collected using diaries; however, it highlighted the limited control over the data and the dependence on participants to make decisions about what and how to write. Communication by telephone was maintained throughout the study which arguably encouraged participation. There was limited control over how often and the way in which participants recorded their accounts in the diaries; however, there was minor structural advice on how to record entries and how much time to dedicate for diary writing in this study. Sargeant and Gross (2011) explored the value of the unclosed diary method in understanding how young people lived with the chronic illness of Inflammatory Bowel Disease (IBD). The study involved six young people, three boys and three girls, between 11-16 years of age, with the main focus of the study around how they managed IBD in their normal daily lives while experiencing the physical and psychosocial changes connected to adolescence. The diaries permitted a glance at how the disease process was built into everyday life. The diaries did not reveal anything of an extraordinary nature within the lives of the participants; on the contrary, it was the level of ordinariness that revealed the most poignant data; the diaries also disclosed evidence of the participants moving back and forth between past and current experiences. This study represented similar motives to capturing the experiences of IDUs that also live with the chronic illnesses of leg ulceration and addiction. It is agreed that when analysing qualitative data, it is not just the extraordinary that is of interest, the ordinary mundane of everyday life is itself of consequence. For the purpose of this study, participants were adults, aged 18 years old or over, to adhere to child protection, ethical issues and clearance. Whatever the age, the emotional consideration to both participant and researcher was an ethical consideration that was acknowledged carefully within this design.

Thomas (2007) explored eliciting emotions in HIV/AIDS research using a diary-based approach and found that solicited text and photo diaries could successfully explore sensitive information around the emotional impact of HIV/AIDS; however, he openly stated that it was unclear whether using these methods of diary recording was psychologically harmful to participants. This is also relevant to the vulnerable emotions that may have emerged in the experiences of IDUs in relation to their leg ulcer and their addiction. Emotions such as isolation, depression, stress and embarrassment from living with their leg ulcer have been previously described in the literature (Morgan et al. 2004; Rich & McLachlan, 2003). It was unclear what emotions could have emerged when recording feelings around leg ulceration and substance misuse, as data relating to both conditions together are not available in the literature. If sensitive emotions emerged, it was important that participants

understood these feelings were normal in terms of recalling experience and that they only needed to record what they were comfortable with and could have withdrawn from the study at any time.

From critiquing the studies relating to the methodology, it appeared that diaries contributed significant to qualitative data around experience, feelings and the patient's journey within the health service. In order to enhance validity and depth to the data after analysis, follow up semi-structured interviews were incorporated into the design of the diaries.

### **3.8.3 Semi- structured interviewing**

Semi-structured interviews were the secondary method of choice to collect and analyse the original data to address the research questions. The interviews were semi-structured including both open and closed questions with the allowance for participants to deviate from this to an extent to capture and enhance their experience. The aim with the semi-structured approach was to facilitate the atmosphere for sensitive information to be captured (Blaxter et al., 2001). The interview was an extension of the story that has begun within the diary. Here, there was an opportunity to revisit some of the diary narrative and give further depth to the journey of living with a leg ulcer.

The interview was an adaptable and powerful tool for eliciting rich data on people's views, attitudes and experiences which underpinned their behaviour and lives (Gray, 2004). It provided participants with time after the diary to reflect on how they felt and share this feeling and experience through the interview. It greatly enhanced the overall narrative around the experiences of IDUs with leg ulceration. The interviews were designed to be face-to-face with a participant information leaflet allowing the participants to understand the study and the researcher's background prior to taking part. The main advantage with this was that face-to-face interviews allowed for the researcher to fully explore responses and clarify any uncertainties that may have emerged from the original diary text, while being able to ask more detailed questions with no literacy requirements for respondents (Bowling, 1997). The interview was an important stage in the narrative as it was at this point when the lone narrative concluded and a new shared narrative begun between the participant and me. This had the potential to develop far beyond the daily experience of living with a leg ulcer as participants had the opportunity now for someone to listen: in this case, not just a random person but someone they trusted.

### **3.8.4 The process of data collection**

The first phase of data collection involved participants completing a diary for four weeks. The diaries were then collected and briefly analysed over a period of one-two weeks following initial analysis of the diaries, respondents were invited back between 7-14 days after the diary to participate in individual semi-structured interviews. Once primary consent was obtained participants were provided with a diary pack which contained the consent form for both the diary and interview (Appendix 10 & 11). The chosen material of the diary was in the form of an anonymised hardback notebook, supplied in an individual plastic folder to the participant with coloured pens enclosed. Bolger et al. (2003) suggested that diaries should be easily portable, allowing participants to carry them around inconspicuously and easily. The envelope pack also included coloured pens, a paper notebook and adhesive paper paste; a diary guidance sheet and contact details for support services were also included within the pack (Appendix 12). Informed consent throughout the study was a continuous renegotiation between myself and the participants.

The diary was designed to minimise disruption and distortion by creating an informal structure with provision of a guidance sheet. Based on Corti (1993) work, using an open format allowed participants to record on a daily basis in their own words their experience of living with leg ulceration. The aim was to enhance the participants control over how they recorded their diary and encouraged freedom of expression. Regular contact with the participant during the diary-keeping process included contact via email/text/visit which aimed to support the participant through the data collection process (Alaszewski, 2006).

Corti (1993) explained that personal documents construct pictures of social reality and are unique in terms of collecting detailed information about behaviours, events and the daily life of the individual. Diaries have a number of advantages over other qualitative methods: the process of recording provides participants words in their original format which can be revisited during the interview to explore possible themes. Diaries facilitated reflection for participants on words, emotions and activities that might otherwise be forgotten (DeNisi et al., 1989). They also provided access to everyday behaviours, experiences and feelings in a relatively inconspicuous manner (Symon, 2004).

Plummer's (1983) *Documents of Life* discussed the ethical implications of using life histories and other types of personal documents to give an insight into the social experience from the participants' point of view. Plummer (2001) highlighted that interest in stories and narratives is often related to the late modern turn in the

breakdown of traditional forms of authoritarian society and repression. At the heart of Plummer's work is the humanistic argument for increased awareness of the uniqueness of local culture and the sensitivity to the individual needs of the population "the need for grounded, multiple and local studies of lives in all their rich flux and change" (p.13).

Plummer (2001) acknowledged the work of Zimmerman and Wieder (1977) on diary data collection in combination with interviews to gain detailed insight and depth into sensitive areas of human behaviour and culture such as sexual activity and drug use. Zimmerman and Wieder (1977) used the diary-interview method as an alternative to participant observation to gain access to behaviours and activities they could not directly observe. Maintaining ongoing contact with participants in a personal yet non-intrusive manner was vital in supporting the collection of data and this was highlighted in the PIS. Plummer (1983) remarked that stories enabled voices to be heard through personal documents where often remains concealed in social research, giving "flesh and bones to the injustices and indignities of the world" (p. 81).

Following diary collection, participants were invited to partake in a semi-structured interview. The interview lasted for up to one hour and took place in the participants' routine clinical area where they have their leg ulcer managed. There were a number of questions which directed the interview in no particular order and these included:

- 1) What was your experience of completing your diary?
- 2) What were the challenges with keeping your diary?
- 3) What did you enjoy/like about recording your diary?
- 4) Has this helped you manage your leg ulcer?
- 5) Has this allowed you to describe how your leg ulcer makes you feel?
- 6) Have you had support/help in completing your diary?
- 7) Has completing your diary helped with managing any of the symptoms of your leg ulcer? (Explore a little such as pain, malodour etc.)

Primarily the interview provided a means of eliciting detailed information about the participant's entries, in particular emergent themes within the text. The interview was

digitally recorded in accordance with participants' consent in addition to hand written notes to support the opportunity for new questions to be formulated. The interview was an adaptable and powerful tool for capturing rich data on personal views and experiences which may have underpinned behaviours and social structures (Blaxter et al., 2001; Gray, 2004). The ability to tell stories gave meaning to words and brought life to language and explored the personal accounts, memories and reflections of these individual creating significance around their experience. I was invited into the personal narrative of these people and was able to gain an incredible personal insight into their lives through contemplating their personal narratives (Taylor & Francis, 2013).

### **3.8.5 Limitations of Diaries**

Diary can provide unique insight into everyday experiences; however, there were concerns regarding the potential effects repeated entries focusing on emotional and behavioural dynamics could unintentionally influence the true concept researchers are trying to understand (Merrilees et al., 2008). The researcher aimed not to focus on what the data "may" have revealed and remained open and empty in terms of expectations as this could have affected the analysis and interpretation. There were noted problems around failure of this patient group to attend appointments for leg ulcer care due to lack of money, transport or often simply oversleeping and missing appointments; this meant that there must have been a pragmatic approach to planning and implementing the diary method while taking the above challenges into consideration (Cook & Jordon, 2010).

Diaries were given initially on appointment through the local leg ulcer clinic, harm reduction teams or ad hoc clinics after recruitment and consent. Follow up calls and possible text messaging with consent was made available and a weekly review at the local leg ulcer service was arranged to monitor progress and answer any questions participants may have had. The chosen method asked participants to give their interpretation of what they experienced from having a leg ulcer and how this impacted on various parts of their daily life from socialising to cooking and looking after or being involved with other family members and friends. Although the diaries were partially structured in order to maintain and help participants arrange their entries in relation to their leg ulceration, caution was taken to avoid leading

questions, excessive guidance and other features that may have caused distortion (Walliman, 2006). This was “their own” experience and the aim was to remain true to this as much as feasibly possible.

Another limitation that may have influenced the quality and legibility of the data was the writing technique and record keeping of the participants. A standardised method of recording was not imposed on participants and they were not to be restricted to write in pen or pencil and if they wished, they could draw in colour. This type of data collection method demanded more time and effort on the part of the respondent compared to the single interview process; therefore, for the purpose of this study the period of entry was four weeks; this was piloted in the first phase. It was not intended to provide financial remuneration for participants for completing the diaries as there were ethical issues around this and payment may have influenced the decision to participate in the study. Financial compensation may have not been important in influencing participation in previously reported studies, even so payment was not contemplated with this study (Richardson, 1994). Despite the fact that financial compensation would encourage participation and recruitment of IDUs with leg ulceration, the vulnerability of this group was significant in terms of their previous or current substance misuse.

### **3.8.6 Pilot**

The design of the study included a preliminary small pilot sample including two participants, to be completed prior to commencing the original design. This involved all the above data collection methods and recruitment. On collecting the data and prior to the analysis, it was agreed with the supervisory team not to exclude this data from the main collection but to include the information within the main dataset.

van Teijlingen and Hundley (2001) highlighted the importance of undertaking a pilot study to review whether the proposed methods or instruments were appropriate to the chosen population or, on the contrary, too complicated. The pilot study did not identify potential practical problems that participants may have found in following the research procedure. Thabane et al. (2010) added that the pilot study was an important factor in data collection and can form the framework of the methodological process. Conducting a pilot prior to the main study increases the likelihood of success by detecting problems that may need to be solved before the main study was attempted (Treece & Treece, 1986). No changes were made as a result of the

pilot; however, it was beneficial in allowing a practice run of the interview and facilitated an insight into the practical timelines of the study.

### **3.8.7 Ethical issues: the diary method**

The process of ethics when collecting diary data was complex and, in this study, involved the participation of vulnerable respondents in terms of their substance misuse and related history. It could be questioned that this form of research could have no direct benefit on the respondents undertaking the study and would have proved timely and emotionally demanding. However, the analysis of their journey aimed to raise a theoretical awareness of the chronic condition of leg ulceration in the IDU population while highlighting success, challenges and possible failures for both clinician and service in the delivery of care. Overall, this study was a small piece in a large theoretical jigsaw around the population of IDUs living with leg ulceration and it was expected that further research questions would arise with the completion of this study. It was important to take into consideration the potential emotional impact on the participant when collecting experiences and journeys using this style of research and, furthermore, considering my role with regards to confidentiality and anonymity during analysis and dissemination (Freshwater & Holloway, 2010). Cloke et al. (2000) discussed the ethical issues in research around homeless people by explaining the purpose and value of the research to the homeless cohort without raising expectations of change or false hope and by remaining honest about the purpose of the study. In the present study, it was considered what would happen to IDU participants when the study was over, what support could have been offered during and after the study, if needed and where and how this could have been available.

A list of local drug and alcohol support services was available for participants to contact, if needed. Throughout the study there was no contact with the researcher through personal mobile numbers or addresses. Instead, a separate research phone and number was used to text or answer calls from participants during the study; however, it was made clear that this was available only in working hours and Monday–Friday. The purpose of the study was not necessarily to provide direct findings supporting the need for a change in services or clinical care for IDUs with leg ulceration. In the event that poor clinical practice was reported to or witnessed, it would first be reported through the appropriate professional and academic channels. Should a notable professional breach of conduct have been witnessed, then as a

Registered Nurse (RGN) this would have been subsequently highlighted to the regulatory body (NMC, 2008).

As nurse-researcher I had to organise my research objectives in line with my professional working duties. I was aware of the complex ethical and professional standards that were involved with this long-term programme of study. The practicalities of conducting the research and exploring the experience of injecting drug users had the potential to expose difficult situations and hard to hear stories. I was aware of the emotional labour of conducting research and the potential impact.

### **3.8.8 Emotional labour**

I was prepared for the study, having worked in complex acute environments with IDUs in the past from my early years as a nurse. I have learnt much from this group of patients and my anxiety then as a novice was my strength now as an experienced nurse-researcher. My profession had equipped me with the experience of listening to patient stories and at the beginning of the DHRes programme I had understood the nature and potential burden of the study I was undertaking

From the onset, I did not dismiss the emotional labour of this design; instead, I decided to embrace it and with this I was able to fully immerse myself in the data collection, transcription and analysis. Participants intuitively perceived that I wished for their voice to be heard. I understood the potential difficulties with recruitment, ethical application and data collection. The participants trusted my commitment to their story and this reinforced my duty to portray their voice using their words in an authentic manner. Also, the duration of the DHRes programme allowed time for me to develop my research autonomy with the support of my supervisory team, which helped strengthen and balance my own emotional resilience through continuous mentoring which, in turn, reduced the labour of the study (Edward, 2017).

## **3.9 Analysis**

### **3.9.1 Process and staging**

Thematic analysis was used to emphasise, examine and record patterns or themes within the data collected. The themes were generated from within the different data sets and aimed to answer the research question/s. The themes became the categories for analysis through a process of coding to create established patterns.

The diaries were read several times over in order to be immersed in the data and to gain a sense of whole from the experiences and feelings of participants (Åstedt – Kurki & Isola, 2001). Open coding was used to explore line-by-line and word-by-word scrutiny of each diary entry with the aim of producing concepts that appeared to fit the data (Strauss, 1987). The qualitative data software tool NVivo Version 10 was used to support this analysis.

Phase 1: Data analysis followed after completion of each individual diary; the analysis was originally brief, within two weeks of diary completion, so as to capture participants with the semi-structured interview before they lost interest in the study. The themes that emerged were used in the semi-structured interviews.

Phase 2: Following the semi-structured interview data collection, a second analysis of the interviews was undertaken and then both analysis sets were explored together for further possible comparable or newly emerged themes. The aim of thematic analysis was to move beyond simple descriptions to identify possible relationships between themes and to examine how emergent themes were interconnected (Pope & Mays, 2006).

The two phases of data collection involved a convergence of methods where the combined approach and relationship “did not imply any particular epistemological claim – that must be based on a theoretical position concerning the intended purpose of bringing the mixed methods together” (Moran-Ellis, et al., 2006 p.51). This method of data convergence involved the generation of a tangible relationship among the two methods while maintaining their integrity.

Fontana and Frey (2005) highlighted the complexity of human experience; the more cognitive methods used, the more likely we are to capture how lives are constructed and stories told. In order to identify potential biases and distortions with the diary keeping process and incongruities between the text and the external reality, the researcher converged the information recorded in the diaries with the interview data (Alaszewski, 2006).

### **3.9.2 Data storage, management and disposal**

From the onset of data collection, when recruiting and securing the anonymity of participants, all hard copies of information were stored in a locked filing cabinet. Information that was stored on a work computer and/ or home lap-top had encrypted access. All the diaries and interviews were transcribed by the researcher and,

although time consuming, this was central to maintaining close contact with the data. All participants anonymised by using a code and pseudonym to protect their identity. Access to transcribed data was stored securely and restricted to the chief investigator. At the end of the study the data was stored securely for up to 7 years within a locked filing cabinet and encrypted computer or personal laptop computer/hard drive and then securely destroyed in line with NHS and University of Hertfordshire Protocols and Standard Operating Procedures. Feedback to participants was offered in the form of a short summary of the findings written in lay language; however, all participants preferred a verbal discussion on the progress of the study. Participants were asked for permission to keep the original hand-written diaries which were stored securely as described above. If participants wished, they retained a photocopy of their diary entries; however, none requested to do this. When presenting data in the form of conference presentations, publications and thesis all names and identifiable information were anonymised.

### **3.9.3 Reporting and dissemination**

This study will be publicised and disseminated in line with the IRAS process and government policy in the UK, promoting registration of clinical studies and public access to research findings affecting health and social care. The research will be registered on a public database for specialist nursing/medical wound-care and substance-misuse research networks. The results of the study will be disseminated in a number of ways including submission for publication in peer reviewed scientific journals, internal reports, conference presentations and submission to regulatory authorities. Anonymity will be maintained when publishing results and care will be taken when publishing details in relation to case histories that could breach confidentiality due to a combination of incidental details, for example age, location and ethnicity. Since commencing data collection I have presented the preliminary work at the London and Irish homeless symposiums in 2017.

### **3.9.4 Conclusion**

The chapter has justified and established the philosophical approach of narrative inquiry as a means to capture the experience of injecting drug users living with leg ulceration. Qualitative methodology using diaries and semi-structured interviews would demonstrate depth of inquiry in an undiluted and unique manner having

placed participants in control of their story. The multifaceted ethical elements of the design have been discussed from the perspective of nurse-researcher and the value of this position to fulfil the research design. The next chapter will present the findings of the study opening with a biography of each of the participants to underpin the presence of the person behind the narrative.

## Chapter Four: Findings

### 4.0 Biographies

The chapter opens with a biographical presentation of each participant in the study. Each individual profile provided a background to the findings chapter and preserved the identity of the storyteller. The narrative has captured the character of the person and embedded this uniqueness within the context and anonymity of their unique story (Corbally & O'Neill, 2014). The following biographies illustrated in part the person behind the lived experience and, by setting the tone and imagery; the reader may appreciate each person's life story. In the beginning was the person and the person was the story. Stories are firstly personal, belonging to the individual, but they can also be social, belonging to a group and to the wider social world in which the story and consequently the person create meaning (Plummer, 2013). To address in full the research question at this point in time in the life of the storyteller and to create meaning behind that experience, there must be submersion in the complete narrative.

### 4.1 Introduction to participants and individual narrative impressions

#### 4.1.1 Oliver

##### Introduction

Oliver was 44 years old and has had a leg ulcer since approximately the year 2008; he reported having starting *"using" in his early 20's.*" At the time Oliver originally developed the ulcer, he did not really understand why this had happened other than this was related to his illicit drug use. Oliver said he *"didn't have a clue"* when *"... leg exploded one morning, got up to go to the bathroom ...blood and mess came out ...kinda guessed it had to do with my injecting but had never heard anything like it..."*

Oliver had a close relationship with his mother; he did not want her to worry about his leg so he often told her a *"little white lie"* that his leg was healing. She would like him to come home so she could look after him but Oliver said he *"can't do that too much pride"*. *"Can't let her see my leg can't handle her worrying"*. He knew his Mum worried *"she's got enough on her plate. You know I have a sister that's mentally handicapped and she has to look after her, so she has a lot on her plate to worry about my leg"*. Oliver talked about having good friends and family; his step dad passed away while he was completing the diary and he described his frustration at

finding the right shoes to fit with his bandages; at one point, he was not going to go to the funeral as he was concerned he was *“gonna stand out like a sore thumb”*. Oliver wanted to *“get himself sorted for summer”*. He was thinking about *“going on holiday, wanna swim but I can’t do that so another city holiday. Everything stops for my leg.... How depressing”*.

Oliver was not in a relationship at the time of the study and admitted to *“not being with anyone for so many years”*. He wanted to *“concentrate on myself at the minute ...I still gotta lot of work to do on myself and do my studies I don’t really want any distractions right now. I’m not getting any younger and I wanna achieve my goals. Time flies for the past 15 years has just gone like that (clicks his fingers) it’s like yesterday I was 30”*.

Oliver has worked in a charity shop; although he admitted to his leg feeling sore from all the standing, he was reluctant to disclose he had a leg ulcer to the people he worked with. *“Can’t tell them about standing as I am embarrassed to tell strangers about it”*. Oliver was *“a very private person and finds it hard to talk about things...I’m very very private”*. He had not told anyone at work about his leg *“I am extremely private. Just take me for who I am not sympathy for this (gestures to his leg) ... doing it on my own”*.

Oliver was at the time of the data collection waiting to get his own flat to live in after moving on from the hostel system. He talked about engagement with services *“Things were finally going my way I could study properly... you know I was struggling to study in the hostel I really was...the noise”*. He was enjoying his new home and personal space *“loving it.... it’s my own private space and things are great”*.

### Narrative impression

Oliver’s narrative appeared well structured in terms of where he was in his journey of living with his leg ulcer, his future ambitions and where he saw his future once his leg ulcer had healed. The past, in terms of his illicit drug use, was difficult for him to reflect on and this was mentioned only in brief both within the diary and the interview. During the interview there was obvious physical and emotional unease and resistance when this was brought up; therefore this was not explored in any depth. To some extent, for Oliver the past was over and he had moved on within his own story; he rightly did not want or deem it necessary to go back to that time in his life. Oliver was calm and obliging during the interview and patiently answered all the interview questions.

At this point Oliver was in the recovery phase of his drug addiction and, in his own words, successfully reintegrating back into society. He was committed and concordant with his leg ulcer care and wanted his ulcer to heal. Oliver's story was centred very much on the "here and now" although his ulcer were still firmly grounded in his daily life. He has been able to build his life around his leg ulcer by studying for a course, getting a job, establishing himself in his own property and having close family and friends.

#### **4.1.2 Emily**

##### Introduction

Emily was 42 years old and reported having her leg ulcers for 10 years. *"They initially started due to catching impetigo from a razor I shaved my legs with. At that time, I had recently (1 or 2 yrs) stopped injecting"*. Emily began injecting when she was 19 years old and she moved in with her first partner. *"He dealt drugs for a living so naturally I had access to a lot of heroin and cocaine. Though I was against needles before I met him within a year I too began to accept hits from my partner...he started with my arms and hands, but within a year or so he was getting me in the groin"*. Thinking back, Emily feels there was a *"valid reason I fell on this dark path.... My mother was a cocaine dealer and Hash. All my childhood drugs and drug – taking was a normal occurrence round our kitchen table. My parents had been Hippies in the 60's too!"*

Emily left home at 18 years old with the guy she had met through her parents who was working as a dealer. *"I thought he was a really nice guy who was saving me from my parent's drug use. Not realising that he was far worst into it than them. I left home with him soon after putting my suitcase and teddy bear! Into the boot of a taxi"*. Emily has two older brothers who *"both had issues with drugs"*. She went on to say that she felt her drug taking *"was somewhat inevitable"*.

Emily reflected on her Mums death in her diary *"Today would have been my mum's b'day and tomorrow will be the 3<sup>rd</sup> year since she passed away...RIP MUM always in my Heart love you dearly XX"*. Emily regularly saw her father and had a close relationship with him. She talked about her father and the impact of her ulcer *"My Dad used to know about it... (The smell of the ulcer) and he won't speak about it anymore, I think it's too painful for him and my son.... em...he noticed it a bit last time and he asked why is your leg so hard and I had to show him the bandage. So*

*yeah I try to keep it from them*". Emily admitted to continuing to smoke crack cocaine and heroin *"more often than I'd like"*. Emily at the time of the study had a partner and they had been together for a few years.

In the past Emily has spent time in prison; she recalled this by composing a poem in her diary titled *"Mr Crack"* (Appendix 13). Emily had a keen interest in art, particularly drawing; during the study she drew a number of images including a birthday and summer celebration (Appendix 14). She also skilfully drew and coloured images of her own leg ulcers (Appendix 15). Emily and her partner are still supported by social services regarding their housing. At the time of the study they were both living in a *"wet hostel"* where homeless people with chronic alcohol problems can continue to drink on the premises in a supportive environment. Emily hoped to *"move on from here"*, she talked about the wet hostel environment *"...they can drink so these people walking around with cans in their hands"*.

#### Narrative impression

Emily's narrative was embedded within the context of openness and honesty and her willingness to share her journey of living with leg ulcers and substance misuse. She did not hold back and wanted to tell her story; in doing so, she reflected on her own life in a complex and wounded manner. Emily coped well with sharing her story but the emotion attached was no doubt at times wearing on her as the teller and also on me as listener. Emily's story was detailed and sensitive; in sharing her story, the listener became a part of it and it was possible to empathise with the emotion, the burden and her resilience. Emily was, to some extent, still in the chaos of drug use by her own admission and, therefore, her leg ulcer care coincided with this chaos in terms of sleeping late and missing appointments to have her leg ulcer bandage changed. Emily was very open about the emotion attached to her past and the impact her drug use had on her life. Her story from the beginning to the end of the interview radiated with the emotions and physical pain she had suffered during her drug use and life with her leg ulcer. The impression from her narrative was that she was very aware of how far she had come: she wanted a better future and her ulcer to heal.

### 4.1.3 Lucinda and George

#### Introduction

Lucinda was 62 and her husband George 61 years old; they had been together for 44 years and married for 35 years. They had three daughters and a granddaughter. Socially, Lucinda admitted not doing much: she often went out with her daughter and spent a lot of her time taking care of her granddaughter when her daughter was studying for a degree. Both Lucinda and George enjoyed reading and taking their dogs out for a walk. George's most memorable film was the Guns of Navarone which he took Lucinda to see in the cinema on their first date.

Lucinda started using heroin when she was 15: *"I started smoking hash then I started... I started drinking VP wine and Demerol cough medicine and that was the very beginning. And then I started smoking hash, speed everything and then when I was 15 I met an old school friend and em... she introduced me to heroin which I then took for the next three years"*.

Lucinda trained as a teacher and met George, there was a time when drugs were not in their lives; however, at the ages of 25 years (Lucinda) and 24 years (George) they were reintroduced to heroin and *"we never looked back..."* Lucinda tells how she introduced George to drugs although he disagreed: *"Yes... I did.....I did. I gave you your first hit I did...How can you say I didn't and everyone thinks it's the other way around everyone thinks that he got me into it but that's not true cause I was 15 when I started and he was 24..."*

Lucinda *"...didn't get the ulcers until the last 5 or 6 years you know injected in the groin for like 10 years, both groins so you would never know in those days when we started doing that, that ultimately it was damaging the arterial system."* The onset of George's ulcers happened first with an insect bite. *"That is the honest truth...no doubt the drugs didn't help..."*

George smoked, had a bad cough and was often short of breath, especially when walking. He also had a bad hip which caused him a lot of pain to walk. Lucinda used to smoke many years ago and gave up heroin when she was pregnant; she breastfed all her children. Lucinda had a history of thrombosis in the veins in her legs which also contributed to the risk of developing venous ulcers.

Lucinda and George have had their leg ulcers for five years and have both struggled with accessing local services for dressing during this time. Lucinda described *"being at the mercy of your GP...my thoughts around that is that basically he had power you*

*know he decided what happened” and “screaming and hollering” to get the care for their legs they needed. Lucinda told how George was “in bed for a year...he couldn’t come downstairs”. George felt at this time about his leg ulcer “I just wanted to die quite honestly...I’m not scared about dying...I wanted to die...”*

Since having consistent compression bandaging, their quality of life had improved immensely and both their leg ulcers were healing. They were looking forward to the future, to a family wedding and going on holiday.

#### Narrative impression

There was a compelling sense of honesty from the onset of this shared story between husband and wife. The story was rooted in tragedy, at times with the theme of loss associated with their drug use. During their interview, the couple pointed out the cost of their drug use *“we have had two mortgages we have lost two houses ...caused a tremendous (said slowly with emphasis) amount of pain to our children, our families even reflecting on our grandchildren”*. The emotional resilience and support for each other was present throughout the narrative, both in the diaries and interviews. There was a clear concept of past, present and future in their narrative, as they described the journey they have come through and the services and clinicians they have met along the way. Although the story of Lucinda and George was set within the chaos of their leg ulcer care, they have managed to continue with normal family life, together as a couple.

#### **4.1.4 Daniel**

##### Introduction

Daniel was 54 years old; he had three daughters and is separated from his wife. He had regular contact with his children and was close to them. He had been working as a postman for ten years when he was introduced to drugs; he described the beginning of his drug use in his diary: *“When I started after a wk I said I’ve got flu, everybody laughed N said you’re sick but C if they didn’t say it aye might have kidded myself on I had flu cos after that every time I didn’t have gear I was sick!!”*. He described the path of drug use as *“...if U R using IV drugs or thinking about it, if you end up like me, you’ll think your 1 of the lucky 1’s cos there’s only 3 places ur going... the Gutter, the Nick or a Box!!”*

Daniel was not entirely clear about his medical history as he described in his diary *"having his groin removed."* He was not sure if this could have referred to the surgical repair of a pseudoaneurysm but he recalled having abscesses *"...aye, aye, I had pink stuff coming out of it, it was shocking..."* He has been living with diabetes since he was 22 years old. He reported *smoking "about 6-8 roll ups a day"* and an alcohol consumption of *"4-5 cans of Stella, to me its shandy it's no that A Cider ...to me its shandy i'd say"*.

Daniel described in his diary when he started *"jagging in 77"* and how he used to *"steal needles... and if I couldn't ney I would go into the bin; the hospital incinerator and I would take them out of that yellow box"*. He understands now how *"shocking"* this is but that was the reality then.

Daniel talked about using drugs and pointed out that for him now injecting is *"long gone"* but admitted to still using at times *"I mean I still smoke brown...heroin...once a fortnight... but I'm down to being a giro junkie"*.

He described in the diary his drug use as *"it's like a day out... a wee day out.... £20 day out... jee wiz I should buy £20 worth of grubb instead you know what I mean I know that cause if I can cut down to spending £100 pound a day on it ...down to spending £20 a fortnight on it... It's time to make that final jump..."*

Daniel has had his leg ulcers for over ten years. The pain and smell have been daily challenges for Daniel living with his wounds. He had real concerns about what would happen had he lost his leg and needed a wheelchair to mobilise. When talking about the future he worried about the possibility of losing his financial benefits, should the ulcers heal: *"well... if my leg gets better they might take me off my money..."*

When asked if he was aware, when he started injecting drugs in his legs, of the physical consequences, specifically the eventuality of developing chronic ulcers and if, in retrospect, that knowledge would have made him stop and think about the risk he admitted *"Oh aye, aye, aye, but I would have still have done it"*.

Daniel paused for a moment during his interview when he reflected on how he enjoyed spending his spare time. *"Taking drugs (laugh) No I do not (laugh) I do not ...in my spare time ...A...I would like to be, get back into photography... I would like to teach the wee ones how to play football"*. However, he understood his criminal past was likely to put this ambition in jeopardy: *"But... chances of that with my criminal past... I don't know. No none of its bad in that way but some people might*

*not want their kids being taught by someone who's got a criminal history. But I would like to do that I would I'd be right up for that".*

### Narrative impression

Daniel was still living with the chaos of his drug use and this is interwoven throughout the narrative, both in his diary and in the interview. At times, the entries in his diary are fragmented as he jumped from one topic to another. Even so, he managed to depict his life now and then; his focus was not on the healing of his leg ulcers. The future for Daniel is tainted by troublesome considerations on what could happen when his ulcer heals; there was a sense of fear within the narrative about the risk of his benefits being withdrawn and his housing affected. Daniels narrative is rich in descriptors of emotions and honesty. He used humour throughout his narrative to soften the hard truths behind his story to make it more bearable for me, the listener, and himself, the storyteller. In his narrative Daniel offered counsel and warning about injecting drug use yet, ironically, he admitted that he would still probably have used drugs even if he had known about the consequences of leg ulceration. There is also the sense of lost opportunity, as Daniel reflected on his ambition to renew his passion in photography and to coach children's football. He recognised that his past convictions were likely to prohibit him from working with children. Daniel's story depicted a disturbing yet truthful reality of drug addiction and he challenged his own past behaviours and choices. His "warts and all" approach to his narrative of addiction demonstrated his view on the unavoidable pain pervading his life story.

## **4.1.5 Isla**

### Introduction

Isla was 54 years old; she married in 1994 and had no children. Isla was a computer scientist and she described her passion for technology "*I was a scientist all my life... I loved computer... I love invention... I always I think what is going to happen in the future... you know like I tell you the thing I can see the future... like I started to work with computers in 1985...*" Isla's preference for computers and typing was reflected by how she chose to report her diary entries: she requested to type them rather than hand write.

Isla described openly her early background and family: "*I came from a working class family, my parents married at 18, they were practically illiterate and after losing their*

*second daughter from some illness that could be treated if they lived near a hospital, that before I born, they moved to São Paulo, a big city in Brazil. They made us study, study and study, my mother used to take us to do test to get scholarships and my elder sister and I ended in one very good school, my parents adopted another 6 kids...”*

She started using drugs in the 1990s and described her introduction to drugs: “...one day I decided to smoke some heroin, my husband was addict for about 5 years... I loved the sensation of flying that gave me, and I started to take in the weekends, after a few nights and soon I was taking every day to feel normal”. Isla talked about the cost and length of her drug use: “By 2008 I was spending £250 per day; I wasted my security I injected about 5 Ferraris and a mansion in the near 15 years I took the drug”.

Isla’s life changed when her husband was diagnosed with lung cancer. “My life changed after my husband was diagnosed with cancer in his lungs and I had to take control over my life to help him... The first thing I did was I bought a litre of methadone and started taking to stop take heroin...”

Her leg ulcers first presented in 2006 and, after many years, she finally accessed services for compression bandaging. After one-year treatment with consistent compression bandaging treatment her venous leg ulcers healed. She currently manages the prevention of recurrences by wearing compression hosiery or stockings on both her legs, every day. This is a daily task she will have to fulfil for life. For aesthetic reasons she prefers the hosiery tights rather than knee-length socks. Every morning, when she wakes up, she applies her hosiery and moisturises the skin of her legs to keep it supple.

Isla talked about where she is now in her life, the challenges of exposing her story and how this made her feel: “No no because... eh... because eh... I wasn’t in that place anymore ...in the pain anymore... I wasn’t taking drugs anymore so in my life at that point it’s not that bad as it used to be... my husband is feeling fine so you see you feel the confident...”

#### Narrative impression

Isla’s narrative was reflective of where she was in her life; her ulcers were healed, she no longer injected heroin or was in the hurricane of drug use. She was positive about where she was at that time in her story and had reflected on the path taken; no longer taking drugs and with healthy healed legs, no open wounds. Her feelings

were also linked to the fact that her husband had recovered and this gave her confidence. Although the remnants of her drug use remained in terms of her physical representation, hyperactivity and restlessness, her narrative was reflective and methodical. She presented her story past, present and future. To some extent, her life, as depicted in the narrative, mirrored the fate of her leg ulceration: they both have healed.

#### **4.1.6 Sanjay**

##### Introduction

Sanjay was 35 years old; he lived with his parents, had recently married and had a young daughter. He had a supportive family but admitted he was frustrated with himself as he realised how impaired his day-life was due to the severe ulcer-related pain in his legs, lack of sleep and breathlessness.

Sanjay had extensive varicose veins in both his legs and reported a history of deep vein thrombosis. Both conditions are independent risk factors for developing venous leg ulcers. He also suffered from asthma and had been actively smoking cigarettes for 25 years; he described his smoking habit in his interview: *“I don’t think I smoke that much now... since my baby has come... cause I can’t smoke in the house... I think I smoke (pause) just probably about 4 or 5 a day....”* Eventually he would like to quit smoking. He also reported problems of urinary frequency which meant he had to get up during the night several times to use the toilet (nocturia); this, combined with the pain from his ulcers, meant that Sanjay’s sleep was compromised. Everyday life for Sanjay consisted of trying to support the household, doing the shopping and cleaning the house; however, he admitted to getting out of breath quickly.

He used to work for a solicitor’s firm, in the local supermarket and energy suppliers. *“I’ve done everything...”* Socially, Sanjay described his routine *“I don’t really go out... I don’t... I don’t sleep much at night... I can’t it’s just ...causing so much hassle. And I sleep probably you know every 2 or 3 days and I’ll sleep for like 14 hours straight... yeah that’s how it’s just been a routine... cause it’s my legs are sore...”*

Sanjay recalled when he first started taking drugs. *“I have been using heroin and crack for over 20 years due to this I have a lot of health problems. When I started smoking I was young... when I was smoking on the foil I was young but em I think when I started em injecting I was in my 20’s”*. Sanjay described in his interview when he stopped injecting into his lower limbs *“Do you know what, I actually stopped*

*injecting for a good... (pause) I think em...yeah a good 5 years...6 years and like and the damage was already done (gestures to his legs) you know and it was so... and I didn't inject for long... I injected for probably about 3 years.... at the most... obviously the damage was done".*

Overall Sanjay had his leg ulcers for about 4 or 5 years. Before making contact with services who could look after his leg ulcers, Sanjay self-managed his wounds for over a year and was not sure what could be done to treat them "...before I came here (to the leg ulcer clinic) my ulcers got bigger and bigger and bigger and bigger and then eventually I got persuaded to come here but I didn't... I didn't know what could be done here I thought it was just like a cut and it would heal on its own... cause I was running around doing what I was doing at the time I thought that's probably why it's not healing".

Sanjay described in his interview where he was then, in terms of his drug use: "I have stopped using drugs and I am taking methadone. I am still in a lot of pain but the painkillers I get do not have any effect". When Sanjay contemplated his current leg ulcer condition and what his hopes were for the future, he remained focused and determined on the expectation of healing: "I want it gone (ulcers)... do you know its 'em... a lot more freedom... like able to get... like the small things get in the shower not having to come every Monday getting these (ulcers ) changed..."

#### Narrative impression

Sanjay's narrative was a unique contribution to the experience of living with a leg ulcer from an ex injecting drug user's perspective. Firstly, he was the youngest among the participants living with a leg ulcer, at 35 years of age. He also had a young wife and a baby; this gave an exclusive insight into the life of a young, married family burdened by the ghost of illicit drug misuse. Sanjay was private about his life yet a glimpse of his every-day routine and struggles emerged from the narrative, through his eyes. Sanjay's practical rehabilitation from drug use and successful compliance to the methadone programme outlined his reintegration into normal life, getting married and having a family. In some respects, the narrative of his leg ulcers remained the last reminder of his past with drugs.

There was another part of Sanjay's narrative that I have referred to as the "untold" or "unfinished" story. For most of Sanjay's diary entries the accounts made were brief and related to the practicalities of living with a leg ulcer: dressing changes, daily life and pain management. The emotions connected to the experience were not always disclosed within the narrative. Some of the feelings were explored in the interview;

however, it was important that, as the listener, I recognised the unspoken tension of feelings left unexplored and the story untold. For Sanjay, that was his chosen approach and direction of his story. There was no critical analysis at the end of his narrative; no right or wrong. In a sense, it was a story that never concluded, it simply continued in a different direction, in another time, from another perspective. Stories and lives are not organised and fashioned in a way that is right or wrong, they are embedded in the person, the character and the life that is being lived, alongside each other, evolving at the time. What clearly emerged from Sanjay's story was that this was where our journey's as listener and storyteller came to a conclusion. Sanjay's narrative portrayed a voice of growth and, to some extent, uncertainty.

#### **4.1.7 Gordon**

##### Introduction

Gordon was 58 years old. He described himself having being brought up in a strict religious family... *"it's embarrassing ...these things are not meant to happen to us you know...they happen to ...you know...(laugh)...this could happen to anyone you know I could quite easily end up on a park bench as well..."* Gordon lived with his brother who also had a history of drug addiction. He had two sisters who lived in South Africa and he was very close to them, they were aware of his drug addiction but not his leg ulcers. Gordon talked about a dual persona *"...being a drug addict... and you know generally I've always lived a different life 'cause I've worked, I've lived a really straight life as well so I've maintained this Jekyll and Hyde type of thing..."*

Gordon worked for a food delivery company in the city *"...I've always worked... I've covered them up... I've had to work"*. Gordon recalled growing up in South Africa and his time serving in the army. He has been in the UK for over 30 years. He described in his narrative the everyday joy of cooking and the importance of eating healthily: *"I enjoy cooking... I enjoy food... you know... I think food is very important"*. The narrative around his work ethic and awareness of eating healthy was an insight into what was important to him and how he viewed his wellbeing, his overall lifestyle despite living with leg ulcers. Keeping fit and healthy was very important to Gordon as he cycled to work every day, making deliveries for a London catering company.

Gordon has had ulcers on both his lower legs for over 8 years. He described how he got his ulcers *".... I got an ulcer from basically eh pushing something into my body which wasn't in a vein you know what I mean so... and unfortunately it was a bit of*

*the drug mixed with the blood... once its mixed with blood and you push it in and it's not in the vein and it sits there and that's what gives you the ulcer generally".* Gordon was adamant to stress the concept that he never injected in the groin and always injected in the lower part of the leg, once the veins in the arms had gone; he also had abscesses in the past and poliomyelitis as a child. Gordon knew you could get ulcers from injecting; mostly he cleaned and dressed his wounds and ulcers himself.

When describing his future, Gordon expressed the desire to go back to South Africa and visit his sisters, *"...once I have got these (ulcers) out of the way... then it's just the last step of getting my passport together and going home for a holiday... because this is the thing (gestures to legs) that has been putting me off for the last ten years..."*

### Narrative impression

Gordon's story was full of intricate details and emotions. Throughout his narrative he described the childhood memories, the phase of chaos and rebellion of his youth and the years that followed. For the most part Gordon did not hold back as he described his journey from childhood in South Africa to his time in London as a chef, his drug use and where he was at this point in time, working for a food delivery company. He was adamant throughout his narrative that there was no excuse for him not to work and he prided himself on this aspect of his life story. Although he talked openly about using drugs, he described his overall lifestyle as clean and healthy. In contrast, his leg ulcers represented to him the shame and embarrassment of his past drug use. His future expectations of returning home after many years coincided with the outcome of his leg ulcers' healing process. His focus at this moment in time was on his leg ulcers to heal. There was a chapter of Gordon's story that was left untold and this was the beginning and reasons for his initiation into drug use. Throughout his detailed interview and diary, he intentionally avoided to disclose this part of this life. During the interview he showed signs of physical unease and tension; he moved awkwardly at times and was restless as he attempted to control his words and gestures. Such a physical reaction in an attempt to conceal an untold story is the most striking element in Gordon's narrative. As there were no obligations to disclose the origins of his drug use, this chapter in Gordon's life remained unwritten. Gordon did not feel the need to include this part of his life within the narrative and, by doing so, this aspect became crucial for this very reason.

#### 4.1.8 Colin

##### Introduction

Colin presented as a shy and quiet 38 year old whose demeanour was almost childlike at times. He spoke throughout his narrative about his mother being his main support at home. His father had recently passed away. He was quite guarded in his body language and in what he disclosed throughout the diary and the interview.

Colin had a medical history of deep vein thrombosis, endocarditis, abscesses and he currently smoked about 20 cigarettes a day although he was keen to quit. He was looking forward to going on holiday abroad despite still having, at the time of the study, a large, active venous leg ulcer.

Colin had experienced leg ulcers for five years; he remembered when they first occurred: *"I got it in Portugal in a swimming pool....yeah I cut my leg in a swimming pool...already a few years before I'd had a deep vein thrombosis and I'd had endocarditis and ah yeah and then I got a leg ulcer"*. Colin recalled the harsh realisation about leg ulcerations *"absolutely zero knowledge before..."* Colin was not aware of the possibility of developing chronic ulcers from injecting. He described *"...ruining my veins... it's just awful... em... yeah... heroin ...is an awful thing... awful drug..."* Talking about his drug use, Colin reflected on the eventuality of having known that injecting could have given him an ulcer: *"It probably wouldn't have affected my drug use cause I used for all sorts of mental problems but it would make me think a lot more...also using clean equipment and everything like that you know what I mean..."*

Colin described that when his ulcer was at its worst he was trying to ignore it but it was just making it worse. Colin had been in jail with his leg ulcers and described resources there for managing leg ulcers as *"...it's horrific to be honest..."*

Colin provided a unique insight into drug use: *"...you got to remember that the best heroin on the street is about 30% which is not a lot so there is 70% of brick dust... old tablets... sleeping pills... your injecting... it's not actually the heroin it's the shit they put in it that ruins your veins and your ...gets you things like this (gestures to his legs)...you know what I mean..."*

At the time of the interview Colin was not working; he expressed the desire to be more active and play more sport. Looking at the future, Colin would have liked to be fitter and healthier in his lifestyle

### Narrative impression

Colin was very much still in the physical and emotional chaos of drug use and his narrative described a journey where drugs may have still been part of his life although he did not disclose still injecting. He was guarded and controlled about what he revealed in his story and there was an element of stable paranoia in his body language and words. He was not yet at the end of his journey through drug addiction and his story was still haunted by his time in prison and how this had affected him. His story was not open and free from boundaries and this reflected, to some extent, where his life and drug misuse currently were. His narrative and matching body language were immersed in dissimulation; there were glimpses of honesty throughout the narrative but Colin did not look settled or at ease with his narrative. His narrative had many gaps in terms of where he was and how he felt. His body language and diary entries illustrated a person holding back.

In some respect, he understood what he needed to accomplish to become fit and healthy again and he appeared to want this, on the surface. His physical presentation, which was not a visible contribution to his narrative, told a different story. His bodily presence portrayed a man on edge, an uneasy mind, still actively using drugs: sweating profusely, dilated pupils and agitation. Even so, Colin managed not to allow his physical presentation to obstruct the story he was willing to tell; the told narrative came across clear and articulate. His narrative was in contradiction with his emotional and physical circumstances and there was a shadow of ambiguity that engulfed his story.

#### **4.1.9 Gregos**

##### Introduction

Gregos was 50 years old. Little was revealed about his past and he disclosed sparse information about his family, mainly within the interview narrative when he talked briefly about his father, mother and brothers. To some extent, Gregos was a loner who described himself “...*to be honest with you I don't have a lot of people around me....*” Gregos used to work in a control station at a mini cab office; however, since his foot ulcer developed, he had not worked for some time.

His social circumstances were very challenging: he was homeless and recalled engaging in sofa surfing at his friends' place, more recently squatting in an

abandoned flat. His ulcer, which affected predominately his foot and toes, caused him excruciating pain and he limped mobilising with the aid of a stick.

Gregos had lived with his foot and leg ulcers for 16 months. He described the beginning of the ulcers as an infection that affected the toes and for some time it subsided with antibiotics; however, the ulcers returned and worsened. He recalled feeling “...I was irritated and desperate at the same time because you know I thought... you know I never experienced anything like that in my life...”

Gregos reported having a history of abscesses in the legs and smoking since he was 22 years old. He described smoking seven to eight “rolls ups” of tobacco a day. Gregos describes his health “...I always had a good health you know... I was blessed with that so you know...”

Gregos started injecting when he was 26 or 27 years old and stopped injecting three years ago. He described never having injected in the groin “...never ...never... in the groin... I never...I mean it was always from the beginning of my injecting history em...I had in my head that I would never do that... if I still need to take drugs I will find another way of consuming them... but you know not in the groin... it was where I could find a vein... on the surface...”

Gregos at the time of the interview still did not have a focus on the future; however, he wished to go back to work as an engineer once his ulcers had healed.

### Narrative impression

Gregos narrative focus in life mirrored that of his current situation in terms of uncertainty. He was homeless, without work and, to some extent, alone. His narrative was prudent in what he disclosed and this coincided with his physical and emotional introversion. He had to shield himself from reality. His physical presentation was guarded and during the interview he sat often with his head down and unable to make eye contact. At times his body curled up almost in a fetal position revealing the figure of a very vulnerable person.

His approach to the diary narrative was very pragmatic, focusing on the practical aspects of the ulcer and on his daily activities. There was a brief insight into how the ulcer made him feel but the depth to which this was explored was limited. Gregos began his interview narrative by trying to access his feelings and experiences; however, remained guarded in the information he disclosed. It is important to note that, of all the participants, Gregos was not known well to me in my clinical capacity and had not long been accessing specialist wound management services. Our

relationship as patient and clinician, participant and researcher, storyteller and listener was new. The feature of disclosure was in its infancy and to some extent Gregos narrative could have represented that of other potential participants not known to the researcher. This was an important finding in the overall narrative account: for this particular population there appeared to be a connection between how well the participant knew and trusted me in my research capacity and in turn what they disclosed.

Gregos still lived a chaotic lifestyle. Though he claimed not to be injecting, it was questionable whether or not he may have still been using some form of illicit substance. Physically, he appeared calm and collected in his demeanour although he was almost paranoid and remained suspicious of people. Gregos very much wanted to take part in the study; however, I am not convinced he was able to embrace this journey as a way to explore his feelings. He may have thought to be ready to disclose how he felt; however, his narrative revealed that exposing the past, present and future of living with a leg ulcer proved too difficult to put into words.

#### **4.2 Exploring narrative impression: the private and collective story**

*“The stories we tell about our lives are not necessarily those lives as they were lived, but these stories become our experience of those lives” (Frank, 1995 p. 22).*

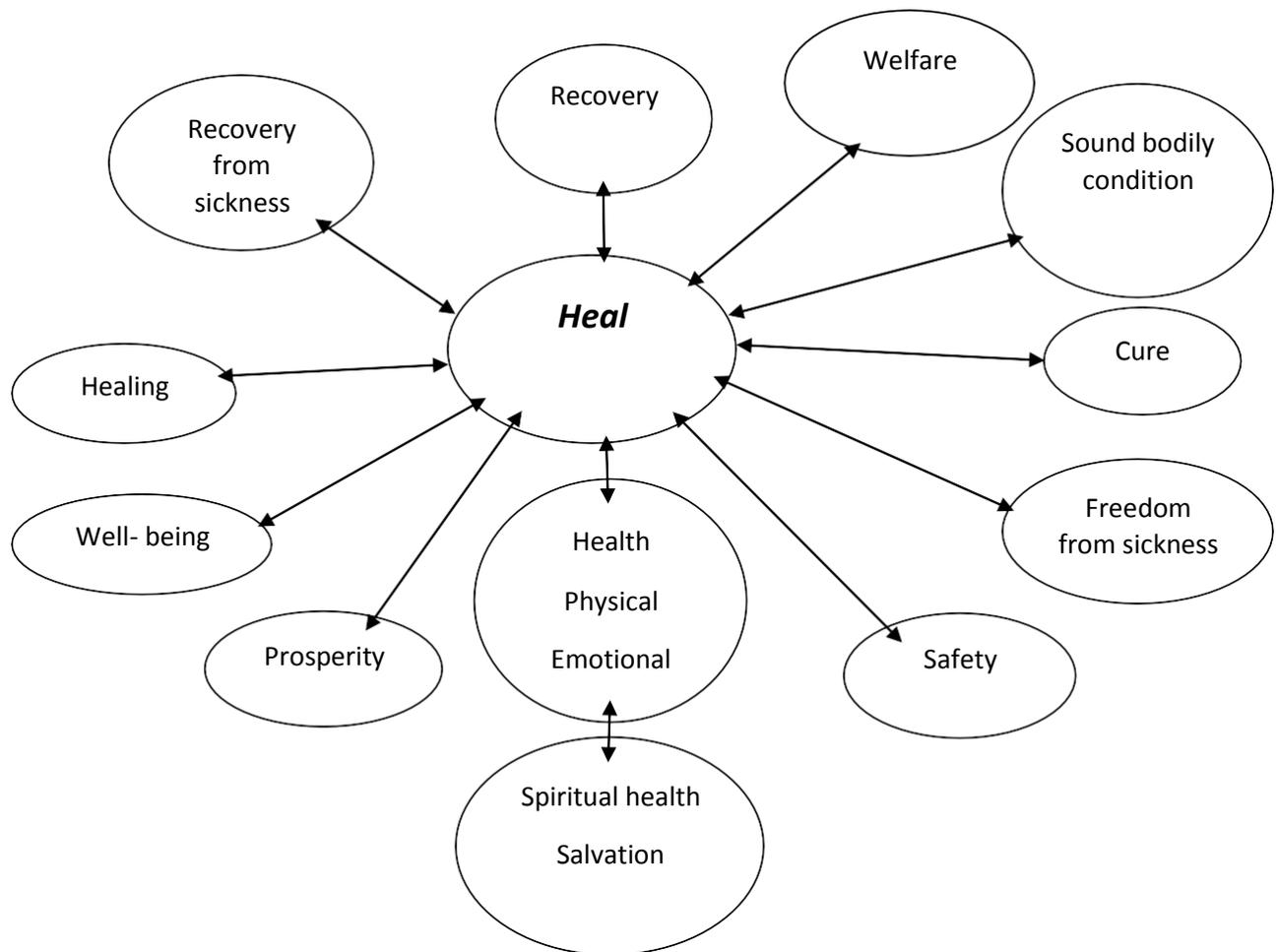
The narrative experience of injecting drug users living with leg ulceration was considered from two positions. Firstly, there was the private story of the individual: past, present and future related to having lived with an open wound and history of illicit drug taking. Secondly, there was the shared story of a culture, a way of life, intricately interwoven in the shared physical and emotional experience of living with an ulcer. Both these aspects coincided and informed each other. Both perspectives have been presented with a view to preserve the unique insight into this group of people as individual and collective wounded storytellers (Frank, 1995). The personal story provided the emotive characteristics that link reader, scientist and clinician together in common themes, both social and physical, such as family, work, love, pain, body image and resilience. The shared experience demonstrated validity in the common physical and emotional suffering of this population and consequently had the potential to improve the way in which patients living with leg ulceration and addiction are understood and cared for. To treat, explore or help the person, patient and service users as clinicians, we must have first listened, understood and appreciated the life lived; for every scar there is a tale to be told, shared and

discovered. Within this narrative the study facilitated a means to express in words the journey lived through the story told; participants could adapt their story as they understood it to be now (Brand, 2015).

### **4.3 The personal story**

The private narrative was an invitation to us, the readers, into the lives of some of our most vulnerable research subjects; an opportunity to listen blindly, with only the words to guide and shape our perception and understanding. It was important to realise that these people wanted to share their story, not just with me but with everyone. Listening and observing the effect of their narrative upon them struck me as an incredibly brave and selfless phenomenon to witness. “If you want to know me, then you must know my story, for my story defines who I am. And if I want to know myself, to gain insight into the meaning of my own life, then I, too, must come to know my own story” (McAdams, 1993, p. 11).

The concept of healing featured within the content, structure, tone and imagery of the stories told. To some extent, it was the very essence of this work and can be found at each connection and interface, within every story. The etymology of the word “heal” reveals a long and interesting evolution in which it has been described in a number of ways. It was important, as I explored the narrative perspective and the concept of healing, that the word itself was presented and understood. From Old English *hælan* (“to heal, cure, save, greet, salute”), from Proto-Germanic *\*hailijana* (“to heal, make whole, save”), from Proto-Indo-European *\*koil-* (“safe, unharmed”). The Oxford English Dictionary (2017) described the word heal in a number of ways; illustrated below the presentation of the word heal in its many forms aimed to capture in some light what this meant to participants.



It was important, when portraying each story, also to understand what the term “to be wounded” meant and how potentially others may have formed their own view. To be wounded was to suffer and to be vulnerable, from the Latin *vulnerāre*, *to wound* (Oxford English Dictionary, 2017). The stories presented here were witness to that suffering which then “comes to understand itself by hearing its own testimony” Frank (1995, p. 169). With all stories there was the presentation of a beginning; this was where participants set the mood and tone of how they wanted to share their story.

#### 4.4 The narrative begins

The narratives began at different points of each participant’s life; for some it was before their drug use and leg ulcer, for others during, and for the remainders the story began at the precise time of the study. One participant simply began with his name and medical history and current health and went from there; there was no right or wrong way. The purpose of the study was to facilitate engagement in the narrative, to listen to what was shared and not to judge or moderate what should or

should not have been told. The introduction set the narrative tone for what was to be disclosed; it set the boundaries for how much participants would divulge. As the story began with the diaries, this empowered and assured participants that they were in control of how they wished to articulate their life, without interruption or intrusion. The authenticity of the experience has in essence validated the narrative stance and enriched ownership: the story was theirs.

For those that shared the beginning, it provided an insight into the person, the life and family at the start of the journey. The beginning, being retrospectively reported, could have been biased by the reflection of where the person was currently, in his or her journey of healing and recovery. It could be argued that the ability to share the intimacy of life before and during drug use demonstrated healing, by sharing ones' wounds verbally. The past in terms of the story was not neatly constructed into the good, bad and ugly. It was portrayed as it has been told, established in the identity of the person behind the illness, forming the foundation of the life story by encouraging the techniques of self-reflection, self-awareness and self-determination. This had facilitated authorship of the story, a sense of wholeness and engaged responsibility of the life lived (Suárez – Ortega, 2012).

#### **4.4.1 Personal openings**

The beginning for participants was often centred on their drug use and the how they were introduced to drugs for the first time. Wherever participants began their story was important as it symbolised where they may have considered the journey of their leg ulcer started. For most of them, this did not coincide with the physiological development of the ulcer itself. The start of the leg ulcer story was directly linked in their words to their drug misuse and, for many, their early family background and childhood. The following quotations present the beginnings of the narrative of the leg ulcer journey as described by those that lived it.

“My mother was a cocaine dealer and Hash. All my childhood drugs and drug-taking was a normal occurrence round our Kitchen Table. My parents had been Hippies in the 60's too! I have two older brothers, both had issues with drugs, so I feel it was somewhat inevitable. Especially as my mother gave me my first pipe of cocaine and chase of heroin” (*Emily's diary*).

“It is difficult to talk about my life the past 25 years, I came from a working class family, my parents married at 18 they were practically illiterate ....They made us

study, study and study, my mother used to take us to do test to get scholarships and my elder sister and I ended in one very good school. My parents adopted another 6 kids to give them education as soon as they build our first house, we slept in the same beds...I was the youngest” (*Isla’s diary*).

“My name is Sanjay and I am 35 years old. I have been using heroin and crack for over 20 years due to this I have had a lot of health problems. I have DVT on both legs I have varicose veins on both legs and I have ulcers on both legs which I am currently getting treatment for. Also I have breathing problems too and get out of breath very quickly” (*Sanjay’s diary*).

“We have been married about 35 but we have been together 44 years....three daughters and a granddaughter. I started using when I was 15 heroin and graduated. I started smoking hash then I started...I started drinking VP wine and Demerol cough medicine and that was the very beginning. And then I started smoking hash, speed everything and then when I was 15 I met an old school friend and em she introduced me to heroin which I then took for the next three years yeah em and then I went to teacher training college and em I something pulled me out of it and then I met G and he lived with me in halls for a year and I still dabbled and then I became a teacher, and when I was 21 I qualified I got a job in London and I taught in London for 5 years then G sisters husband died and his parents asked us to move to X so we moved to X and I bought up... we brought up her son for 5 years he was 5 she was completely distraught I have never seen grief like it. He was 20 years older than her I’ve never seen anyone in my whole life grieve the way his sister did; but during that time we eventually bought a house I was teaching he was working we came to London to see “The Who” and got reintroduced to heroin” (*Lucinda’s diary*).

“First Entry – Friday 4th July 2014: Before I start with my current situation regarding my ulcers I need to reflect on the past 4 years. I have been undergoing treatment for ulcers for the past 4 years, 2.5 years of dressings by district nurses at home, then 55 weeks in Hospital and since approx. May 2014 at a community Hospital. The ulcers are on my left leg and are comprised by an occlusion in my left groin. All the ulcers apart from the one on my ankle are a result of injecting in my groin. The ankle one is from the bite of a horse-fly” (*George’s diary*).

“My ulcer started in Sept 2008 or thereabouts. I didn’t really understand why this had happened other than my illicit drug abuse. Initially I can say that I felt embarrassed as I had prided myself on never having anything like this in all my years of abusing

drugs. I felt shame when telling my friends about it but it seemed to be tenfold the shame when telling my family” (*Oliver’s diary*).

“I’m still not sure exactly what is the plan but once a start, I’m hoping I’ll go on, I missed my app. Yesterday (Wednesday 11th) with Sister \* and I really don’t like letting her down be cos her and her team R I think the hardest working unity not just N \*\*Hospital in all hospitals us went 2 in London... I’ve been a postman (was) 4 ten year, I know how important your plates of meat are (feet) u can lose an eye, arm, ear, finger but you lose just a leg U R Finished. If it did happen and God forbid, but I’d hope that a friend would pull the chair away!! Anyhow on 2 something else, if U R using IV drugs or thinking about it, if you end up like me, you’ll think your 1 of the lucky 1’s cos there’s only 3 places ur going... the Gutter, the Nick or a Box!!” (*Daniel’s diary*).

“Colin’s Diary (leg ulcers): Woke up leg in a lot of pain at the moment, Always when I first get out of bed and very itchy. My train broke down and I had to walk all the way home missed my appointment but I got to see the nurse this afternoon and she gave me real hope that I can beat this, and I had my leg dressed, the pain has gone down but it is still very itchy. I finish the day more optimistic than I have been for a long time. I’m going tomorrow to get new trainers and then my new bandages” (*Colin’s diary*).

“A brief history of my leg ulcers: As an intravenous drug user I have suffered from ulcers on both legs and arms. I have had the ulcer on my leg for almost 8 years long enough to effect the shape of my calf on my right leg. This wound closed completely about 3 years ago but has since re-opened. The ulcer on my left leg I have had for about 5 years. Both ulcers I have cleaned and dressed at home due to the fact I find the GP rather unsympathetic and that your condition is entirely your own fault. I am certainly not looking for sympathy but can do without being treated like that at my age” (*Gordon’s diary*).

“Monday 7th March: Bandage was changed at the \*\* (specialist clinic-hospital). This is the first time after 7 months that there is an improvement. Pain is still present but I am still taking co-codamol + ibuprofen 4 times a day” (*Gregos’s diary*).

The beginning, the incipit of the participants’ journey, was significant as it set the style for how the stories would unfold. For the majority, this meant a revelation of emotions and thoughts related to their wound: what caused it, who cared for it and how they lived every day with it.

Each participant's introduction provided an insight for the listener and the reader into about what they considered important or maybe not so important. For many, these were valuable memories: some good, some bad but nonetheless a shared account of what they recalled as their truth.

#### **4.5 Narrative tone**

A powerful, emotive tone ran throughout all the stories, with pain featuring strongly both in the diaries and interviews. Like healing, pain had many meanings and interpretations: it arose from the emotions and physical descriptions of living with a leg ulcer and the life journeyed. We gained an insight into grief and what had been lost from the life lived. There were strong connections between the physical and emotional characteristics of the narrative described: pain, grief and healing. These narrative features ran parallel to each other and were interwoven as the stories unfolded. Each descriptor influenced the other; pain disturbed sleep and mood whereas healing increased mobility and happiness, ulcers' malodour created feelings of embarrassment and isolation. The stories had an enormous power of self-reflection and self-inquiry: the ability to look within and see ourselves for who we truly are. Many participants were at different stages of their recovery from drug addiction and this stage of healing was revealed into the narrative tone and physical and emotional experience they exposed.

##### **4.5.1 Crime and punishment**

The uncovering and exposure of participants' feelings related to the experience of living with their leg ulcer was uncomfortable, at times upsetting. Within the text there was a palpable sense of pain both physical and mental. Pain, shame and grief were undeniably evident within the text, yet for the storyteller this difficult reality needed to be expressed, demanded to be told and wanted to be heard. An extract has been taken from each of the participants' diary and interview that expressed the pain of the journey. There was a common belief among participants that they deserved to suffer with their leg ulcer as a consequence of their drug history. Metaphors of shame, grief and pain transpired throughout the narrative and reflected the participants' feeling of self-identity, self-blame and self-punishment. As the findings have demonstrated, participants have strongly associated their drug use with their own weakness and self-destruction.

## **Oliver**

“Initially I can say that I felt embarrassed as I had prided myself on never having anything like this (gestures to leg ulcers) in all my years of abusing drugs. I felt shame when telling my friends about it but it seemed to be tenfold the shame when telling my family”. “Pain has become my best friend. Hate to moan about it cos can imagine my friend like me are fed up with it, even though they don’t say” (*Oliver’s diary*).

### *Oliver’s interview*

Researcher: You talk a lot about pain through your diary...

Oliver: “Yeah a hell of a lot of pain I went through”

Researcher: Tell me a little bit about the day to day...say when you get up in the morning...

Oliver: “Get up in the morning, getting up is a person to itself. ‘Cause you kinda have to get up and if you stand up straight away the blood rushes down and the pain is just immense. So, you kinda put your foot over the side and go from there and then lift it back up so it kinda gets used to the blood flowing again”

Researcher: What about sleeping in bed?

Oliver: “Oh that’s impossible some nights I couldn’t get to sleep...”

## **Emily**

“Such a long time ago I am trying to remember how I felt? I know it’s always made me feel ugly and ashamed. I think takin drugs is how I’ve dealt with my feelings, which is possibly the worst thing I should do because it just enables me to turn a blind eye and pretend it’s not happening. But it’s a vicious circle because the more I took the more I need. And then the addiction took over and self-neglect begins. And so, although I’ve always said they (ulcers) began from Impetigo not abscesses or fixing, I do know that my body, veins were not working as they should do because of previous IV damage. So the Impetigo didn’t heal the same way it would have if I’d never injected” (*Emily’s diary*).

“Due to caring for the wound myself it has been rather painful today. Also having run out of painkillers. Sometimes I think I would benefit more from a district nurse visiting me at home” (*Emily’s diary*).

“Noticing a lot of pain with my leg. And the truth is I’ve only myself to blame in that firstly I haven’t been keeping up with getting it dressed regularly & also that I run out of painkillers. So other than keeping the ulcers clean + hygienic and elevated I’ll hold on till Monday when I WILL! Get to clinic and see the nurse for dressing and DR for pain relief. Also ask whether it should be swabbed for any possibility of infection” (*Emily’s diary*).

“I am upset with myself in my self–neglect of my leg ulcers. I do think that drugs have an effect on this. On one hand it reduces the pain but more importantly it overall is the cause of the wounds that create the pain. So, if asked, I would have to say that Drugs are the reason I’m in this condition. If I could turn back time for certain I would cherish the gift of life and my body. And I would love myself instead of constantly harming my body & mind. So, I am concentrating in doing something to change my lifestyle. Which will be a long process, (after all it’s been a lifetime of using that got me to 42 years of age!). This said I am going to apply for detox & rehab to come off methadone, but in the meantime, reduce & stop taking street drugs on top. I believe this will help speed up the healing of the ulcers a great deal. I know that I will have to wear compression hosiery for life” (*Emily’s diary*).

#### *Emily’s interview*

Researcher: Just thinking for a minute ...how has your ulcer impacted on your life in the last ten years? If you think you are 42 now ten years ago you were 32 so in the last ten years how has this impacted on your relationships?

Emily: “It has yeah yeah...it has a lot of impact. I hid it from...Actually I think when we got together (talking about her partner) it was healed in fact yeah, I know it was that’s about eight years now...so it was healed then it wasn’t so bad then it started to flare up a couple of years after being with him. Yeah I feel embarrassed it affects greatly on relationships yeah”.

Researcher: Do you think the ulcer may affect your intimacy?

Emily: “Yeah yeah definitely...”

Researcher: What about being in hospital with a leg ulcer; do you think clinicians know how to deal with a leg ulcer?

Emily: “Not all, not all of them no...”

Researcher: Do they know how to treat it?

Emily: "Not all of them no..."

Researcher: Do you think your history impacts on how clinicians treat you?

Emily: "Yeah...agree...yeah I think there's... I've come across three nurses that won't tolerate... that don't tolerate people that who got drug history".

Researcher: Really, have they said that to you?

Emily: "Some of them yeah... some of them some of them wouldn't actually work with... in X hospital for instance there was a nurse there and she wouldn't work with people who had a drug problem. Her attitude was very clear she wouldn't even come around and make beds with people who had a drug problem."

Researcher: That was hard. How did that make you feel?

Emily: "Yeah, yeah I felt a bit low"

### **Isla**

"When you take drugs, your life is around the time when you score, you spend most of your time waiting for the drug dealers to deliver, and sometimes is fake and you have to restart all over until you get a bit...The ulcers were very smelly and painful, but sometimes you feel like you deserve the suffering. You want to punish yourself for being weak, a liar and a junkie... (*Isla's diary*).

"They were so painful that I took about, 20 pain killers and I had several antibiotics, but did not get better, I stopped to use the bath and wash my body by sections; I went in \*X hospital. But the guy in the pharmacy wanted to charge me for the medicine, so I ended up without" (*Isla's diary*).

### *Isla's Interview*

Researcher: Tell me about the pain, Isla.

Isla: "Oh my God...I was taking painkillers like paracetamol and eh... Ibuprofen...eh..."

Researcher: Describe it to me

Isla: "I was... taking the maximum full and drink and drink and try to forget you know gentle laugh) you know you try to forget. I start to learn to live with the pain it's like I said...it's like you feel you deserve the pain...you know...maybe you have to suffer to learn ... to...to learn to...to learn to not do anymore...you understand.... I

learnt...it's the pain and... It's like eh that I was thinking the pain...I was deserving the pain..."

Researcher: So when we talk about the pain...can you.... if you were to describe, how did they feel?

Isla: "Oh my God they felt terrible....it was like that...pain...pain...pain.... PAIN" (loud dramatic saying of the word pain) pain...pain...pain.... **PAIN!!!** (Even louder and more dramatic)

### **Lucinda and George**

"I have spent the last 4 years in varying levels of pain ranging from on a scale of 1-10 at the best a 0-10 (since I've been going to the community hospital \* every week) and 8/9 out of 10 at times during the preceding 4 years. In the year I did not seek treatment (4 years ago) I was in agony. On waking up and getting out of bed the pain of my ulcers (which looked like shark bites, 2 on my left leg, and 3 on my right was like being stung by bees and stabbed with hot poker. This would come and go throughout the day, get less by the evening and come and go throughout the night, but was always worse when putting my legs on the floor in the morning. Once I started treatment at the doctor and variously at the hospital the pain was probably less at times but appointments were so "hit and miss" I just got used to living with the pain and taking up to 12 Ibuprofen a day as well as using heroin practically daily. I am no longer taking any drugs." (*Lucinda's diary*).

"Every day for 55 weeks I took approx. 8 Ibuprofen, 6 Gabapentin and 5-6 Tramadol plus frequent street heroin for pain I had an epidural at the Pain Clinic. Nothing worked. I just wanted to die. Since going to community hospital, the pain has been minimal (minimal has been underlined in red) – no comparison to before. Spent nearly 6 months in bed. Sleep badly affected for 55 weeks!" (*George's diary*).

### *George and Lucinda's interview*

"Sunday the leg would be smelling, by Monday, Tuesday it would be smelling and dripping, Wednesday, Thursday, Friday it would be stinking, dripping, my daughter would say "Mum my friends can't come in" we would have air freshener everywhere and he... was... in... agony..., he was in bed for a year he couldn't come downstairs he couldn't take the dogs out, he wanted to die, they sent him for an epidural... epidural in the end with me screaming epidural didn't work. I used to go to the Department and scream at them "This needs to be done twice a week you can't do this ...you can't...this is wrong".

Researcher: Did it scare you, George, having your leg like that?

George: "No...I just wanted to die quite honestly...I'm not scared about dying...I wanted to die..."

Researcher: What in your words is good care? What do you expect nurses to be able to do?

Lucinda: "Not to feel any stigma because of the drug addiction".

Researcher: Do you think they feel that, the nurses?

Lucinda: "Oh yeah definitely...no not all certain people...no I'm not generalising....you just feel scummy...you know you just feel scummy because you've got this through drugs. So you kinda expect to be judged".

### **Daniel**

"Ma leg is on fire A woke up at 3am and the pain it's like the blood has been cut off at my knee, I finally got up at 7am and just feel either it was so well cleaned?? Or the bandages R 2 tight, so 2Day A took them off N put new 1's on!! No difference I'm scared to lie down N case I don't get another night's sleep. My leg is on fire, I've spoken with chemist but she's telling me 2 go 2 Accident & Emergency" (*Daniel's diary*).

### *Daniel's interview*

Daniel: "Em...and then it would let other people know they don't need to hold back, alright that you've got the bad leg and your leg smells ...and it does smell sometimes (high pitch) I mean I have seen people on the bus going "sniff" (demonstrates this) and I know it's coming from me and I'm like that (low laugh). I've had to get off buses sometimes I felt that embarrassed and go on the next one..."

Researcher: That's hard that's really tough

Daniel: "Silence...But once people (participant eating) I used to go to this place XX and get it done and see when you walked in there, see the smell it would scare most people away".

Researcher: Does it frustrate you...with it not healing?

Daniel: "Na...I mean I know I will never wear shorts again, I'll never take the wee ones to the swimming, well the wee ones are too old to go to the swimming with their Da. But I know I'll never wear shorts again...which is ney big, ney big deal..."

Researcher: You don't know...

Daniel: "It's just the smell \*\* (said with conviction)".

### **Sanjay**

"I have been admitted to hospital a few times due to my leg's pain and due to my legs swelling up to double its size. I currently have a four-layer compression on both of my legs which gets changed twice a week by nurses to help heal the ulcers on both my legs. I have stopped using drugs and I am taking methadone. I am still in a lot of pain but the painkillers I get do not have any effect" (*Sanjay's diary*).

### *Sanjay's interview*

Researcher: Do you think in one way the pain limits you more than your wounds...if you know what I mean?

Sanjay: "Yeah...I...I...I think they come hand in hand...because like...I can't go away for a holiday for long periods you know...like this needs to get changed otherwise it will just get worse and worse...I... like the pain stops me from doing a lot of things but so does the ulcers as well so I think they have. They both have their part to play..."

### **Gordon**

"New bandages and a welcome relief as bandages stiff, smelly and dirty. Always a relief to have no bandages if only for 20minutes" (*Gordon's diary*).

### *Gordon interview*

Researcher: Tell me about your experience of pain

Gordon: "I mean some days I remember eating like about 18 paracetamol in a day you know just eating cause the pain was so severe from getting an ulcer and that...ah no I carried on working day in day out...My brother used to say he used to come back to work and see me and he said my face used to be contorted with pain you know and he used to feel so sorry for me you understand I used to pretend that nothing was wrong you know.... "

## **Colin**

“My leg is very painful today I have new pain killers. I think I walked a bit too much yesterday evening it really burns and stings. Generally, I am ok looking forward to new dressings. I am going today to get new shoes that are a size big for me. Good evening diary my leg is in severe pain today it’s like a burning sensation and other than lying down it’s too much to bare. Tomorrow I’m going to try and go back to the clinic and get my new dressings I can only hope that makes a difference. I must see the Doctor for some pain medication because this is not fair” (*Colin’s diary*).

### *Colin interview*

Researcher: Tell me about how pain makes you feel

Colin: “I’ve been in a place where I just about I wanted just cut off (gestures to the leg) .... Just get it over with...you know what I mean...Cause it feels like it is spiralling out of control and you can’t do anything about it...like it would scare me just to look at it...do you know what I mean...”

## **Gregos**

“Bandage was changed at the hospital. This is the first time after 7 months that there is an improvement. Pain is still present but I am still taking co-codamol + ibuprofen 4 times a day” (*Gregos’s diary*).

### *Gregos interview*

Researcher: How do you describe what the pain means to you?

Gregos: “Yeah...em...what words...em...desperation...you know...”

Researcher: And does it go on?

Gregos: “Well you know yeah...I mean you know...you go through...I mean personally I go through this madness this kinda... like this madness phase of like you know it needs to stop... it needs to stop... and this is all I can think of... how I can make it stop... you know em....”

Researcher: So it had a big part in your life

Gregos: “Yeah it becomes obsessive! (said with conviction)...you become obsessive with pain I mean you know...not only that em...small tweaks and stuff you think shit is it going to start again...you know...just like you’re... your on 24 kinda like your on

alert all the time...like you know is it ...oh it's a twitch... oh... you know like that ...just thinking is it going to start from now... or any minute...or you know cause you think oh I can't go through this again..."

The collective narrative of IDUs living with leg ulceration came with a character of counsel. The stories told are steeped in self-blame and punishment, pain and anguish. With this some participants portrayed a narrative of caution, a way perhaps to deflect or manage the self-blame by focusing on warning or preventing others from a similar harm. Hindsight had played a part and the storyteller's offered their life experiences as an example of deterrence.

#### **4.5.2 Caution**

Throughout the narrative there were glimpses of caution and warning from the storytellers about the consequences of using drugs and in turn how this affected daily life living with an ulcer.

##### **Daniel**

Researcher: It's hard to come to the clinic (leg ulcer) that often when there is stuff going on...

Daniel: "Aye, aye aye, I mean most people still use, I mean I still use but I'm down to being a *giro junkie*."

Researcher: But you don't inject, do you?

Daniel: "No, no that's long gone".

Researcher: Do you think if you'd known back then what you know about the ulcers would you have...

Daniel: "Oh aye, aye, aye, but I would have still have done it"

Researcher: Would you?

Daniel: Em (nods)

Researcher: That's an honest thing to say (participant makes a funny face gentle smirk)...

Daniel: "I mean people think, like that if somebody with Hep C would you use their needle. No I wouldn't ney no I wouldn't ney....Aye you would at 2 o'clock in the

morning where are you going to get a needle at 2 o'clock in the morning; you can use mine but I've got Hep C, I'll clean it I'll clean it...

Researcher: It's so easy done

Daniel: "Of course it is \* I've had people saying no no no...they are telling lies...honestly. I mean there are people selling needles at midnight for a pound each, you get them for nothing and they are selling them at midnight for a pound each".

Daniel: "Like I say I'm a giro junkie...once a fortnight..."

Researcher: I have no idea what that is (Laugh gently)

Daniel: "Well I use brown once a fortnight... Heroin ...once a fortnight...giro junkie"

Researcher: But you don't... (gesture to inject)

Daniel: "Na...na..na I smoke it.... it's like a day out... a wee day out... (R= is it?)...£20 day out...jee wiz I should buy £20 worth of grub instead you know what I mean I know that cause if I can cut down to spending £100 pound a day on it...down to spending £20 a fortnight on it..It's time to make that final jump..."

Researcher: It's difficult though?

Daniel: "But it shouldn't ney be....\* I mean I get a lot I get Methadone I get like I say these diazepam but I don't really want them..."

### **Sanjay**

Researcher: So you hurt your leg with the hover, that's how it first appeared and then it went on and on until you came here?

Sanjay: "It just went on and on it cleared...it's like a first it was just the one leg and it cleared and then it came back again and when it came back it was on both legs".

Researcher: And what were the main problems when you first got it, did you know what it was, and did you know how you got it?

Sanjay: "No...no I didn't know what it was...I heard people say they got ulcers and this and that I didn't think it was an ulcer I thought it was just a cut. I was quite naïve about it... you know I just thought it would heal on its own you know it's not as bad as I didn't I didn't put any thought into it really I just let it do what it was doing and it just got worse and worse."

Researcher: Did you see your doctor about it?

Sanjay: “No...I didn’t even see my doctor... listen no one...I had it in my head like...its not to do with injecting it’s probably a cut I’m not injecting...”

#### 4.6 Expressions of self

For other participants their manner of expressing their experience and potentially separating or filtering their self-blame was achieved through art and the potential wider benefits of the shared story. Emily composed a poem that described her time in prison:

##### Mr. Crack

“I ask myself “What Is Jail”?

It’s a place they send you when you don’t get bail!

Locked in a room they call a cell.

When no-one comes when you ring the bell!

Where you see you’re cellmates takin the piss.

Why am I in a place like this?

I blame that geezer “Mr Crack”!

He’s hard to shake when he’s on your back.

The very first blast is the only one.

But to tell you the truth he’s not much fun.

He’s got me out there committing crime.

And now I’m in here doing time!

Mr Crack, you’re nothing but evil,

All you do, is destroy people.

I was so weak to fall for you.

And now I’m here feeling sad + blue

Well Mr Crack, hear what I say

Jail saved me, I got away” (*Emily*).

##### 4.6.1 Art, humour and language

Lucinda decided to draw her leg ulcers and described how they looked (Appendix 16). “They looked like shark bites, 2 on my left leg, and 3 on my right was like being stung by bees and stabbed with hot poker” (*Lucinda, diary*).

Oliver’s diary and interview revealed the double-sided, love-hate relationship with his leg ulcer and how it made him feel.

“I hate the constant ritual of dressing changes. Enough is enough now, just want it

over....Sometimes just want my leg of, still would miss it like mad though. How mad is that.”

“You don’t think about it on a daily basis you just got so used to it being part of my life so it might be strange not actually having to have it dressed...really weird kinda bitter sweet”

Humour is used throughout the narratives as a way to release tension for both storyteller and listener. Daniel used humour and metaphors to detract from the seriousness of his drug use. His description of himself being a “giro junkie” depicted the ironic humour that his current drug use was a social habit, one he was in control of and described in a casual manner

Daniel: “I mean most people still use, I mean I still use but I’m down to being a giro junkie.

Researcher: Do you think if you’d known back then what you know about the ulcers would you have put one and one together, would you have put the two...

Daniel: “Oh aye, aye, aye, but I would have still have done it”.

Researcher: Would you?

Daniel: (nods and smirks)

Researcher: That’s an honest thing to say” (participant makes a funny face gentle smirk)...

Metaphors are also used to identify how IDUs felt about themselves or how they perceived others felt about them. Oliver described in his diary, and later in the interview, how it felt not being able to take part in sports with his friends because of his leg ulcer.

“My friends went swimming without me again know I can’t go, but that doesn’t stop me feeling like the odd one out! Know how lepers feel!!”

He revisited this again in his interview.

Oliver: “You do you feel like the odd one and it’s like if I took the bandages off I couldn’t go in any of the water, everyone would be staring at me I just feel just really like I was diseased...( pause and stumble words) or obviously people don’t know what it is and they just think Oh God it’s a massive wound and they think Blood Bourne viruses all the rest of it which I can understand so you know even though

I've got a clean bill of health that way it just makes you feel like a leper, you just feel dirty, unclean".

Contemplating the narratives in their entirety they present the person from a number of different perspectives; the good, the bad and the ugly. This is not unique to the IDU population as the nature of humanity depicts all these characters within the person. Due to the nature of drug addiction, deviant behaviour and subsequent detriments the character of the bad and ugly is accentuated. The findings have shown from the perspective of IDUs that medical professionals often see their situation as self-inflicted.

"Both ulcers I have cleaned and dressed at home due to the fact I find the GP rather unsympathetic and that your condition is entirely your own fault. I am certainly not looking for sympathy but can do without being treated like that at my age" (*Gordon's diary*)

"I've had battles with doctor's nurses, doctor's surgeries, the care in doctor's surgeries....We changed...we were with a doctor's surgery for 20 years and they were absolutely appalling... (*Lucinda's interview*)

Isla: "...the NHS system the way they are doing now is failing the people because you know they have all those clinics that take lots of people and they have lots of doctors working those places...you don't see the same doctor...you don't see the same guy every time you go there it is a different doctor and I have to explain about my addiction about the pain I feel (said in a frustrated way) I feel like I have ..I think...feel sick all the time to my stomach.... I ask please give me a doctor...a family doctor..."

Daniel: "...I mean...like every every every doctors I've been ta I say... can you do a bandage.. what... four layer ....whats that for... and I'm told na... I mean all they...all they see is junkie... I ain't touching it...I mean I had one like when I got the abscess and eh well in my left cheek...I've got eyes in the back of my bum (laugh) and she was cleaning it....But the woman she didn't...either she didn't want to touch it or she was feared in case she'd get something..."

Researcher: Maybe she didn't know....

Daniel: "Aye, aye, maybe, but to me it was more like she didn't give a damn what I...what was wrong with me..."

*Emily described some of her encounters with clinicians.*

Researcher: Do you think your history impacts on how clinicians treat you?

Emily: "Yeah...agree...yeah I think there's I've come across three nurses that won't tolerate... that don't tolerate people that who got drug history".

Researcher: Really, have they said that to you?

Emily: "Some of them yeah... some of them some of them wouldn't actually work with... in X hospital for instance there was a nurse there and she wouldn't work with people who had a drug problem. Her attitude was very clear she wouldn't even come round and make beds with people who had a drug problem..."

The findings from the narratives, as emerged in this study, have the potential to contribute to the qualitative work, showing that IDUs with leg ulceration have clear clinical needs and requirements when living with leg ulceration. By co-designing services for patients through the use of narratives, there is the potential to enrich and improve current general health services for IDUs. The use of narratives to develop relationships between clinician and client may also help developing trust and promoting concordance. The narratives presented in this study clearly articulated the many complex health care needs that IDUs with a leg ulcer may experience: pain, malodour, reduced mobility, leaking ulcers and embarrassment. These important disturbances and co-morbidities greatly impair the quality of life, negatively impacting on both physical and psychological healing. The findings from this study have the potential to greatly contribute to the current evidence.

#### **4.7 New beginnings: the life after**

The narratives also portrayed, for many, an end to a chapter of their life and the beginning of another. For some, this coincided with their leg ulcer healing. Again, the concept of healing and being cured of their wound featured strongly in the stories. A new beginning also meant acknowledging the practicalities of what would happen once their ulcer had healed and no longer required services or dressing. Many participants had lived with this wound, and the physical care attached to this, for many years; the topic of how they felt now that this phase of their life was coming to a close and the emotions attached to this were analysed.

### **4.7.1 Healing**

#### **Oliver**

Researcher: When you started getting the compression for your venous leg ulcers, how would you describe that?

Oliver: "Oh God, it was life changing, cause I could do more things, I could get up without worrying about the massive pain and I could for instance going to the toilet I'd literally wait until I was bursting to go to the toilet cause I didn't want to get up because I knew the pain I'd be in".

Researcher: Are things better now?

Oliver: "Oh God, yeah I can pretty much do what I want now. I don't take pain killers any more, I don't take any pain killers whatsoever".

Researcher: Do you think there is a link between how you feel in yourself and how your leg...

Oliver: "Yeah it does there is definitely a connection cause if you feel down you automatically start cursing your leg and you feel the pain and your leg feels more and your kinda in tune more to the pain. When you're happy you don't think of the leg or it doesn't seem to hurt as much or its maybe there but you don't really notice".

#### **Gregos**

"I am already looking forward to my next bandage change. I think that the more frequent change the better the ulcer gets. Since I started 3 times a week changes the difference is obvious even to non medical professionals like me. Still in pain, still taking the same amount of pain relief... I have appointment at the \*\* hospital for my usual bandage change. Pain is manageable and is kept to comfortable levels. Still feeling the swelling of my toes but is a lot less discomfort....I went to \*\* hospital today. The nurse was able to clean between my toes and not feel pain. Last week she couldn't do this without causing me a lot of pain, stress and anxiety. The wound is improving. The dark areas have gone and changed to a reddish colour" (*Gregos's diary*).

#### **Gordon**

"Legs comfortable due to new bandages and in no ways sore. Both legs starting to feel uncomfortable and I can only put this down to not working and lack of movement for both legs. Seems like when I was at work I spent less time of thinking or being

aware of the ulcers. Thank goodness bandages changed today. Legs much the same always feel okay when bandages new and clean" (*Gordon's diary*).

"A change of bandages today. This has now become the highlight of my week. The 20 minutes of no bandages while the ulcers are cleaned are most enjoyable. Plus the comfort of new bandages. Things don't get better" (*Gordon's diary*).

"Well the beginning of the year my legs get better. Looking forward to going back to work as I am less aware of my ulcers and bandages when I am working. Also working stimulates the blood and legs somehow making things feel better" (*Gordon's diary*).

"Another good day. Everybody really pleased with progress so far which in turn makes me feel better. Over the last week I seem to have more feeling around both ulcers, which is hopefully a good sign. Last day of diary. I am happy to report that the situation with my ulcers is far better than when I started this diary" (*Gordon's diary*).

#### **4.7.2 Bittersweet emotions**

##### **Oliver**

Researcher: How do you think you will feel when its healed because it's going that way, how do you think it will feel to be out of bandages?

Oliver: "I will be excited but I will kinda miss it as well. It's like having a pet or child to look after you kinda have to plan your week or your time around it. You know..."

##### **Lucinda & George**

Researcher: Its part of life and your journey...together look where you are now. What are you planning; what's on the agenda?

Lucinda: "Mine were all healed and then a few weeks ago a little bubble came up and I was devastated...I was...It was so wonderful not to have dressings... I'm just glad it's now that it will be done by summer. By em you just feel free.

Researcher: Are you planning a holiday, your daughter's wedding?

Lucinda: "We are going on a cruise...X getting married next year. Well I get my teachers pension in April....so this is all leading up to going on a cruise in August".

## **Isla**

Researcher: Let me ask you so how would you sum up your journey with the leg ulcers?

Isla: "It was good because it gave me more confidence...I didn't feel pain anymore...I could walk without problem I could put my shoes you know... I could do... I could go out with high heeled boots... because when I was with my ulcer I couldn't do eh boots ... I used to use the biggest shoes ... but before I was usually a size 10...but you know the thing is improved my life because I started to walk...instead of getting buses anymore... like today to come here I walk...before I used to come with taxi... so that improved the life is the journey".

## **Sanjay**

Sanjay: "I want to be swimming with my daughter, there's no way I can do it with my legs like this and then even when the bandages are off the veins popping out you know people seeing that. I probably will you know when probably get long shorts or something get in there but yeah I wanna be doing that ... you know just small things like that...".

### **4.7.3 Closure**

The conclusions of the narratives of injecting drug users living with leg ulceration have two levels of interpretation. Firstly, how the narrative has concluded for the storyteller and how the shared story has impacted on his or her life experience. Second, the impact of the narrative on the reader with the potential implications on clinical practice and future research. The possible interpretations of the narratives depend, to some extent, on the position of the reader in respect to his/her opinions and previous experiences. My position, as a reader and interpreter, is that of clinician and researcher, student and teacher, writer and listener. Each stage of the narrative inquiry brought in different intrinsic interpretations and conflictual moral standpoint but ultimately the role of the interpreter surrendered to the true essence of the story and became irrelevant. What truly mattered was the authentic interpretation of the narrative which could only have been achieved through the relationship on which the narrative was built; the foundation of the narrative was built on trust. With this study, a new chapter in the untold story of injecting drug users living with leg ulceration has just started being written, setting the premises to unfold new experiences and stories in the way they are lived, in the constant change of time and place.

## **Chapter Five: Discussion and Conclusion**

### **5.0 Overview**

The purpose of this chapter is an attempt to synthesise and interpret the material gleaned from the findings and literature and to come to new understandings of the landscape. To explore the experiences of injecting drug users living with leg ulceration through the narrative lens of those who are wounded storytellers. The discussion has sought to inform theory and practice; this chapter will reflect how the findings differ and challenge existing knowledge, practice and opinion about the IDU population and their current and past lives whilst living with an open wound. The chapter has been shaped and guided by the narrative of current or ex IDU's stories of living with a leg ulcer, interpreted by a tissue viability nurse-researcher who was known clinically to participants. The author played the dual role of clinical and research nurse; furthermore, I was both listener and narrator of the participants' personal stories. There was a constant reflexive thread throughout the research that underpinned and influenced the ideas presented. In the realisation of the trust granted by the participants, I acknowledged the importance of my role in facilitating the storytelling, in the accurate and sensitive portrayal of their story and in the responsibility of interpreting them.

### **5.1 Underpinning what is already known about leg ulceration in drug users**

There is significant evidence to suggest that venous leg ulceration impacts significantly on quality of life in the general population whereas only a small body of work identifies this in the drug user cohort (Charles, 1995a, 1995b; Finnie & Nicolson 2002a, 2002b; Palfreyman et al. 2007; Pieper 1996a, 1996b; Walters et al., 1999). Recent evidence continues to support the early work that highlighted the psychosocial impact of living with a leg ulcer conveying the message that we should be addressing people holistically to treat not just the wound in isolation but the whole person (Cunha et al., 2017; Isaac & Watson, 2016). International studies focusing on the general leg ulcer patients' quality of life highlighted the impact of such condition on employment and family members (González de la Torre et al., 2017; Kouris et al., 2015; Lloret et al., 2015). Recent economic data has also illustrated the financial burden of chronic wound care on the NHS with particular emphasis on chronic leg ulceration. In the years 2012/2013, an estimated 2.2 million people presenting with a wound were managed by the NHS with an annual cost of £6 billion; 19% of all wounds were leg ulcers (n= 730,000) (Guest et al. 2015; 2017). Recent literature has begun to explore the implications of such growing economic burden in chronic wound

care. This is a paradigm shift in the socio-political management of leg ulcer care in the UK and internationally. However, the economic aspects cannot overshadow the personal and psychosocial facets. This study represents a contribution to the social and clinical literature in the form of the narrative, the voice of the wounded, offering exclusive insight into the lives of those considered marginalised and vulnerable, in London, today. This chapter will pull together the main emerging themes within the narratives and discuss them in relation to existing theories and practice with a view of integrating the new evidence into the wider theoretical understanding of leg ulceration in people who inject drugs (PWID). This has the potential to shape and change policy and practice. The study demonstrated a number of contributory sociological insights and argued the everyday societal preconceptions of what makes PWID vulnerable and marginalised. The notion of vulnerability, the impact on the social world and the potential for new meanings will be discussed extensively in the chapter. The social identity of the participants, and what this represents, emerged as an underpinning theme throughout the findings and is interwoven with other elements such as stigma, pain and judgement.

The findings present a unique insight into the diverse background of London's IDUs who have lived with a leg ulcer. The sample represented a heterogeneous and diverse group of people; the group comprised of three women and nine men with an age spanning between the third and sixth decade of life, two of the participants aged 61 and 62 years were married and were grandparents, the youngest IDU of 35 years was married with a young child and wife. Their cultural and socio-economic background was extremely different; nine of the participants were born in Britain, of those nine, eight were white British with one participant of British Asian ethnicity. The remaining three participants had lived in the UK for many years and were born in the continents of Africa, South America and Southern Europe. This ethnic diversity reflects the demographic population of London. All the participants had worked in the UK at one point, now only one of the participants was in active employment, the remaining nine were unemployed.

The gender, age, marital status and ethnicity of the participants did not discriminate against the narrative findings. The themes were comparable across both datasets of diaries and interviews relating to the lived experience of leg ulceration. This group of people have similar physical and psychological experiences of the leg ulceration and coping mechanisms. The data did not reveal any deviance relating to age, gender or ethnicity. This has the potential to benefit the standardisation of pathways of care for leg ulceration in this population nationwide. The variance in ethnicity and age reflect that of a large cosmopolitan city; London has provided this backdrop. It would be of

interest to replicate or conduct a similar study in other urban or rural areas to establish different or similar findings.

This particular sociological narrative has the potential to be of socio-political interest as social and health care evolves. These contemporary stories may hold importance in the way wound care is reviewed and services for IDUs are co-designed in the future. The narratives have the potential to have contributed in positive and negative storylines, the insight has ability to change and complement the way in which qualitative wound care data is collected and disseminated for hard to reach populations.

## **5.2 Acknowledging the IDU leg ulcer population through their story**

The extensive literature review revealed only a paucity of studies related specifically to the care of leg ulceration in the UK injecting drug user population. Prior to this no previous research has been reported with a view to understand and represent the voice of injecting drug users who have leg ulcers. This could explain, to some extent, why the practice of wound care with this population remains unpredictable, mainly relying on a selected number of health care professionals with specific clinical interest or contact with this group. The use of the narrative storytelling to give meaning and life to the experience of IDUs living with leg ulceration was a unique research strategy aiming at understanding the existence of a group of people who are hard to reach and somewhat guarded in their lifestyle. The fundamental question regarding this design was whether participants would have embrace this style of research as an opportunity to tell their life story and how would they have chosen to voice it. Although there remains a call for further clinical research in the field of wound care with a focus on the care of wounds for IDU's there has been an influx in recent developments at government level to tackle the problem of drug use in the UK.

### **5.2.1 Building on current policy: a place for narrative inquiry**

The Home Office (2017) policy update for Drug Strategy recognised the need to build on their focus of recovering and maintenance to achieve and maintain lives free of drugs and crime. The Strategy involved collaboration from health, academic, the justice system, housing and welfare and adult protection to ensure a comprehensive action plan to tackle the problems of drug misuse and criminal activity. Strategic actions include a prevention plan focusing on deterring young people from the initial

contact with drugs, targeting criminal activity that profit from the sale of drugs therefore restricting the availability and reducing demand and offering the chance of recovery from drug use at every point in life. The report highlighted the growing number of older drug users with the average age of people in treatment increasing from forty to sixty years of age. The Advisory Council on the Misuse of Drugs (ACMD) established a working group to explore the numbers of older drug users in the UK and the health care needs of this cohort. Within the action phase *Building Recovery*, service user involvement was considered key in the design and implementation of drug and alcohol treatment services. It could be argued that narrative-led health needs assessment should be incorporated into a new revolutionary design of health care services meeting the needs of IDUs. PHE (2017e) have issued updated guidance for PWID to include infection risks. The Unlinked Anonymous Monitoring (UAM), with support from PHE and over 60 specialist agencies working across England, Wales and Northern Ireland, have collected surveys of PWID since year 1990. The survey measures the prevalence of HIV, hepatitis B and hepatitis C in the IDU population who are in contact with specialist services. They also monitor the level of risk and behaviours within this group. The data from this survey has been used to develop preventative health education campaigns for IDUs service provision and development in the UK (PHE, 2014). The findings of this study have the potential to influence current educational packages delivered to clinicians working with IDUs aiming to improve effective working relationships.

The portrayal of life affected by illness and addiction by process of narrative inquiry could be incorporated into the way the NHS evolves to meet the challenges ahead. As pointed out in the NHS Five Year Forward View, the UK population is expected to live longer with complex health issues “*sometimes of our own making...with one in five adults smoking, a third of us drink too much alcohol and under two thirds of the population overweight or obese* (NHS England, 2014 p. 2)”. Furthermore, there is a strong focus on improving access to mental health services for the future of the NHS, with a staggering one in four of us experiencing mental health problems. The update on the Five Year Review (NHS England, 2017a) emphasised the cost effectiveness of early, mental health intervention. However, the review failed to emphasise some of the issues surrounding mental health such as homelessness and illicit drug use. The narrative inquiry may play a key role in reducing harm associated with complex health care needs such as mental health and illicit drug taking. The diaries are a valuable tool to capture the story behind alcoholism, eating disorders, drug abuse. By hearing and analysing the participants’ stories, a greater understanding of their

lives, their history, personal beliefs and lifestyle, can be reached; this may allow the answer to how health care can reduce harm associated with these destructive lifestyle choices. The narratives in this study are used to acknowledge the life and experience of IDUs living with leg ulceration through their words in their everyday reality and health care encounters. Rance et al. (2017) acknowledged how *“Narrative analysis attempts to honour the challenges and the complexities of the accounting work.... providing a valuable counterpoint to other qualitative approaches”* (p.2230).

Although narrative of IDUs living with leg ulcers, as presented in this study, is an absolute novelty, narratives have been previously used to understand the lives of drug and alcohol users to improve the treatment services. Narratives may help to develop and optimise care by facilitating the collaboration between service users and provider moving away from stories of “exclusion and disconnection, to narratives of opportunity, inclusion and possibility” (Wilson et al., 2013, p.114). The findings showed a group of people who have embraced storytelling as a way to be heard and to monitor the progress of their leg ulcer healing (including the malodour, pain and reduced mobility). The findings offer new medical insight on skin and vascular conditions in PWID.

### **5.2.2 Skin and wound complications in IDUs: waiting to be heard**

Guidance updated in December from the Department of Health (2017) offered direction for how clinicians should treat people with drug misuse and drug dependence problems. This detailed document emphasised in the *Health considerations* section (Bacterial and other infections), the importance of assessing superficial skin infections at the injection sites. It estimated that approximately a third of people who have injected psychoactive drugs in England, Wales and Northern Ireland had reported an abscess, sore or open wound during the last year. In Scotland 20% of those attending needle and syringe programmes presented with the same conditions (p. 172). The documents simply referred to “skin ulceration” without mentioning the aetiology of the ulcer, therefore failing to direct physicians towards differential diagnosis and appropriate treatment strategy. Furthermore, there was no reference to the long term implications of chronic ulcerations and recurrent wound infections. The document, however, underlines the importance of pain management. This topic will be discussed later as pain was a consistent and repetitive feature through all the narratives presented in this study. A recent study has acknowledged the increase in opiate overdose related deaths and the growing aging population of IDUs. There was particular concern for the increase in skin, soft tissue, and vascular

infections (SSTVI) and data from a London hospital demonstrated that 58% of hospital admissions in PWID were related to SSTVIs. The study called for a more proactive monitoring of SSTVIs and work to improve access to services that would provide wound care and support concordance was also highlighted (Lewer et al., 2017). The findings from this study have supportive qualitative data to complement this study on the experience of IDUs living with chronic leg ulceration. As often is the case across multi health disciplines particularly in the nursing and medical field local research such as this is often not disclosed until after the work is completed and published. Nevertheless, this work is an important development in practice and addition to theory in the recognition that SSTVIs are a cause for concern and hospital admission among the IDU population.

Coull et al. (2014) collected data from 200 hundred participants in needle exchange and methadone clinics across Glasgow, Scotland establishing the prevalence of skin problems and leg ulceration in a sample of young injecting drug users (age range 21-44 years; mean 35 years): 60% had experienced a skin problem and 15% of all the participants reported having a leg ulcer. The study highlighted a concerning growth in the prevalence of leg ulceration in the young injecting drug user population compared to 1% of the adult Western population and called for clearer guidance for health care professionals and drug users on skin problems. The findings from this study concur with Coull et al. (2014) that harm reduction initiatives and governmental focus must also include the aftermath of injecting drugs, raising awareness of skin damage and the long term vascular implications of injecting drug use. Skin problems and the prevalence of leg ulcers are increasing; subsequently the narrative of those who have experienced injecting drug use and living with a leg ulcer is particularly important as it can support the awareness and health campaign to ensure health care for injecting drug users is inclusive of all physical needs.

The narrative has also led to the reflective conclusion that all clinical conditions of the integumentary system, hair, skin and nails, should be addressed within a specific framework and recommendations for care during and after injecting drugs to help prevent long term skin problems. The World Health Organisation, regional office for South-East Asia, (WHO, 2009) recognised ulcers, venous and arterial injuries as common health problems associated with injection-related injuries. It also provided detailed advice on the causes of injecting drugs on the venous system, chronic damage to the veins leading to venous insufficiency and clearly stated that venous ulcers are a direct result of damaged veins from injecting. The guidance offers advice on injection techniques and preparing the skin as well as treatment advice for wound care. Yet again, there is no correlation in this document between venous disease,

compression therapy treatment and prevention and healing. There is however, an important correlation between the risk factors associated with infection, such as the development of bacteraemia and septicaemia from untreated injection- related infections and ulcers. With this in mind, there appears to be justifiable clinical reasons why the care of IDUs with leg ulcers should be considered from a broader health care perspective.

### **5.2.3 Pain: the elephant in the room**

There is an overwhelming description of the physical pain that each of the participants have documented while recounting daily life with their leg ulcer. Each participant describes in detail the excruciating pain he or she have suffered and the barriers encountered when trying to find a solution.

*“I have stopped using drugs and I am taking methadone. I am still in a lot of pain but the painkillers I get do not have any effect” (Sanjay’s interview)*

George’s pain was so bad at times he “wanted to die”. The common thread within the findings demonstrate the complexity of managing pain in this group of people. On the contrary, compression therapy, once instigated to treat their venous ulcers, helped alleviate the pain. The findings do not address in detail the solution to their chronic pain; however, we learn that participants had a better experience and improved analgesia once in contact with the appropriate services to care for the leg ulceration. The studies on the care of venous leg ulcers in PWID are all conclusive suggesting the usefulness of compression therapy, reporting satisfactory healing rates. Consistent compression therapy is key when managing venous leg ulceration in PWID (Acton, 2008; Cook & Jordon, 2010; Wheatley, 2007)

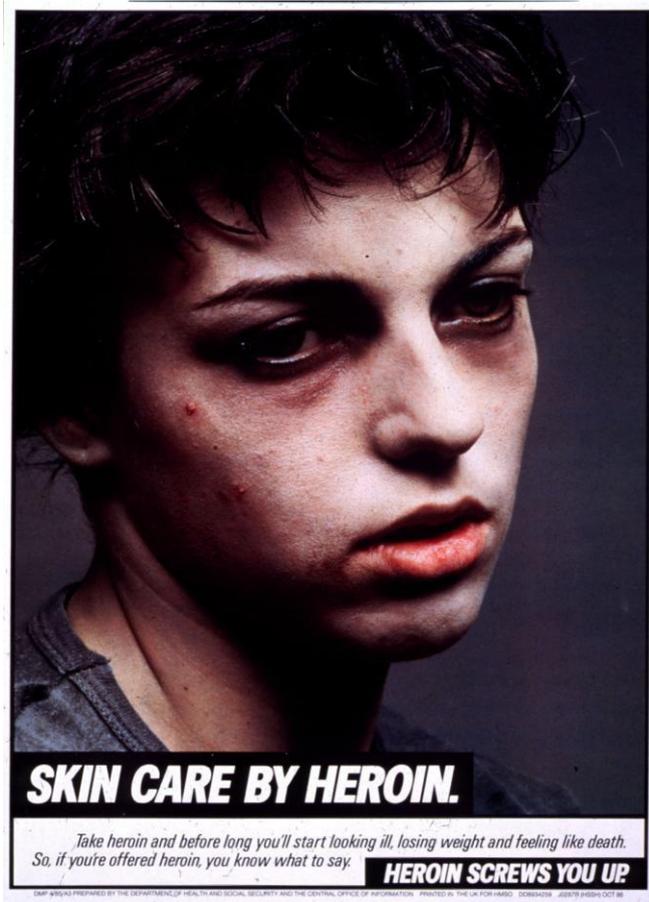
Overall literature failed to deeply explore the full physical impact of injecting drug use, more specifically the damage to the lower limb vessels and the long term vascular insults, resulting in chronic venous hypertension and venous leg ulceration. New evidence around the implications of injecting on the vascular system and skin health and hygiene plainly emerges in the narrative findings of IDUs seeking health intervention for their leg ulcer problem. The narratives clearly identified a shortage of trained clinicians and service provision for the leg ulcer care and a lack of knowledge and understanding from clinicians regarding their condition. The narratives have the potential not only to portray the physical realities of living with an open wound but also the mindset of how leg ulcers affect the way IDUs view themselves and how they perceive others to feel about them.

### **5.3 Identity and self: the complexity of multiple realities**

There are multiple realities to the complex stories presented and, as health care practitioners and scientists, we must strive to align what is the reality of living with leg ulceration as a PWID and what we choose to see and judge. The stories presented for this study have been shared to learn, to understand and to grow from the experience of others. There was overwhelming inclination for participants to tell their story of living with a leg ulcer, to be heard and the desire to make an impact and a difference on the leg ulcer services provided for the benefit of other IDUs. There is also the impression that by sharing the personal story, this group of people sought to be viewed in a different light and not to be stigmatised by their drug history or leg ulcer.

There is no doubt that the public perception of a drug user with a leg ulcer is one of fear of the unknown or prejudice. We often fear what we do not understand or have not experienced. If we can increase awareness of the realities of drug use we may lessen the fear associated with it. With fear can come labelling, ignorance and misunderstanding; however, by raising awareness, fear could be replaced with empathy, compassion and enlightenment (Seele, 2017).

Narrative imagery and narration run parallel and can be a very powerful tool to raise public health awareness. An example of this was recognised recently by the British Medical Journal (Shepherd, 2017), as PHE exhibited historical health campaigns to showcase the significance of strong imageries used by governmental and non-governmental public campaigns. The 1986 antidrug campaign from the Department of Health and Social Security has been displayed to demonstrate the way in which imagery can impact on our perceptions and how stories can also be attached to the images that we create. There needs to be caution about how officials and policy makers campaign with the use of visual representation of a population such as people who use drug as demonstrated below. Raising awareness in this way can instil fear which in turn has the potential to form distorted versions of the complete truth that can potentially result in social rejection, avoidance and blame. It is also important to mention that although the visual appearance of the participants is not recorded for this study none of the participants came across as the picture below. They may have been tired, in pain or irritable at times but these are traits we all experience in our daily life. For the majority of participants who took part in this study the picture below misconstrues their physical presence.



1986 antidrug campaign from the Department of Health and Social Security

The narratives in this study challenge the conventional images associated with the lives of IDUs. The stories do not subtract from the tragic and shocking truth of drug use and wound care. They do, however, present another perspective in terms of reflection, hope and recovery. The imagery emerging from theirs is one of bravery, resilience and selflessness. In some respects, these characteristics defy the medical literature and the common morality depicting PWID as chaotic, non-compliant and interfering with their wound care (Iyer et al., 2011; Iyer et al., 2012; Simmonds & Coomber, 2009; Treloar & Rhodes, 2009). The literature is often limited by the health carers' perspective bias. The findings argue that PWID are not fully represented in the literature for the people they are or the life they lived. Future policy and wound care practice need to be inclusive of the voices and experience of PWID if we are to progress in an equal and comprehensive manner.

The stories demonstrate other dimensions to the individual with a history of injecting drug use; they identify the person amongst the chaos: the father, grandmother, daughter and friend behind the drug user. Their social networks and displays of affection, kindness and acts of selflessness challenge the social norms and the general public imagery. The findings have revealed new aspects of the lives of PWID: the participants are protecting their family from the knowledge that they have a leg ulcer.

*“Told mother a little white lie today said my leg had pretty much healed. She says come home let me look after you can’t do that too much pride. Can’t let her see my leg can’t handle her worrying” (Oliver’s diary)*

In the next paragraph the extent to which IDUs embraced the opportunity of narrative to explore their feelings is analysed.

#### **5.4 Narrative inquiry: giving voice to the wounded**

The use of narrative to depict the experience of IDUs living with leg ulceration has exceeded expectation. The participants not only self-portrayed the physical experience of living with a leg ulcer but also presented a rich and, at times, graphic content to their lives and bodies during and in the aftermath of drug use. Participants identified their leg ulcer and drug history as one entity; thus the emotional experience is interwoven and the two aspects cannot be severed from each other. The physical and emotional representation of the lived experience is steeped in self - incrimination, pain and loss. Participants blame their lifestyle of drug use as the cause of their leg ulcer. They use metaphors to describe shame and grief suggesting self-blame and punishment. Participants have strongly associated their drug use with their own weakness and self-destruction.

*“You want to punish yourself for being weak, a liar and a junkie...” (Isla’s diary).*

Self-punishment is perceived as the act of expiation to atone for the guilt of having inflicted suffering upon themselves and their families as a consequence of their drug misuse. One of the greatest penances is the loss of life-time, wasted by their addiction:

*“If I could turn back time for certain I would cherish the gift of life and my body. And I would love myself instead of constantly harming my body & mind...” (Emily’s diary).*

Moreover, the shame felt from developing leg ulcers as a result of injecting is a recurrent theme. The findings also suggest that there is perceived societal punishment and stigma for their deviant behaviour of injecting drugs and participants perceive this hostile attitude from others as self-inflicted. The concepts of guilt and societal blame run parallel to each other and one appears to impact on the other in a continuous cycle. These concepts are encored as stigma. The question is could more be done to normalise and somehow embrace this blame through narrative: by studying closer the stories of PWID, reaching a better understanding and identifying new paths for recovery and healing. Is there healing to be found from reliving these narratives through the eyes of the reader? Could narratives be used to bridge the societal gap between what we think we know, what we fear and what the reality of people who inject drugs and live with leg ulceration is?

Inui and Frankel (2006) acknowledged that as practising clinicians, we must connect and challenge the concept of otherness or difference in patients and ourselves in order to establish relations and build bridges between the self and other. How we relate to and engage with patients is as important as how we diagnose and treat the condition. We cannot treat the person unless we appreciate the individual and the narrative needs to be built together to include everyone. When caring for PWID with leg ulcers it is important to consider: "In this story, where am I? Where is the individual? Where is the common good? What, then, should I do?" (p. 415).

Embracing the person behind these narratives may cause public discomfort by disclosing the lived truth of leg ulceration and drug use; like most unknown phenomenon, the beginning of a new truth or reality takes time for adaptation. Once established in practice, narrative inquiry and "storybridging" could be a revolutionary way in which to initially engage people who are marginalised and deviant in behaviour, not exclusive to drug use. Storybridging refers to the use of stories as a tool for bridging the gap between health inequities by utilising personal stories to form the basis of the health narrative intervention; this method could be used to co-design wound care services for PWID by establishing from service users what matters to them in terms of their leg ulcer care (Boeijinga et al., 2017).

The findings confirm the original hypothesis that stigma is a detriment of health for people who inject drugs whether internalised or perceived and can have a devastating impact on the individual, negatively affecting his or her psychological recovery, well-being, reemployment and reintegration into normal life (Link & Phelan, 2001). Page (1984) argued that stigma may change over time in terms of the people

targeted and in the way society views them. Focusing solely on the health and illness is a limitation; despite current policy and agenda, more work to promote the person behind injecting drug use should be encouraged. It could be argued that merely focusing on the illness of injecting drug users may exacerbate the societal and internalised blame. The design of this study emphasised the “living experience” of drug users with a leg ulcer and, therefore, encouraged participants to embrace and provide the narrative of their whole life, not just their drug history. The reflective themes that participants relived in their narrative will now be further explored.

#### **5.4.1 Reliving the story: changes in time and identity**

The findings clearly identify recurrent elements of self - blame and punishment throughout both datasets. The narrative proved to be effective as a medium for participants to re-enact their current or past traumas by expressing aloud how they felt, by physically writing their memories down and reliving the entries again through the interview process. Acknowledging the personal stories of people who have injected drugs has potentially multiple implications: from a wider sociological perspective, the findings have the potential to reject the social hostility and exclusion towards the so called “drug user”, demanding that the social order re-examines the way IDUs with leg ulcers are portrayed, by emphasising their full life story and not just focusing on their addiction.

The narratives may represent for the storyteller both a constraint and a release from reliving their experience (Rance et al., 2017). The findings supported this duality: the narratives of IDUs living with leg ulcers were both cathartic, by releasing their emotions in a trusting, controlled and safe manner, and constraining, by realisation of their responsibilities in the leg ulcer occurrence and of their past behaviour obstructing healing. It allowed participants to reflect on their life living with their ulcer. The expressions of self-blame and punishment are not isolated to people with a history of drug use; studies have demonstrated that cancer patients have been shown to portray feelings of stigma, self-blame and perceived blame, particularly in colorectal, lung and breast cancer patients (Phelan et al., 2013). The evidence on self-blame and punishment in cancer-related illnesses and drug use does not appear aligned in the literature. Cancer-related stigmas have grown increasing attention from researchers in recent years and have been shown to have a profound impact on body image and intense feelings of body stigma and shame with many breast cancer patients suffering from physical and cognitive impairments and fear (Wang et

al., 2017). However, the sociology literature seems to discriminate between drug use and cancer-related stigma and body image.

Etherington (2006) challenges the usual societal negative focus on the drug user concept of analysing the way drug users identify with themselves through stories. In a quest to encourage drug works and educators to move away from the view of “fixed identity” towards the notion that identity, like the stories themselves, is an ever-changing interpersonal process. The findings in this study show the constant flow in time of feelings, experiences and personal growth. The negative expressions of guilt, punishment and shame are not necessarily as a static emotion felt at the moment of writing but as a fluctuant memory they recall and honour in time.

Identity within these narratives changes as participants move from the loss and chaos of their drug use, living with their leg ulcer, to the hope of new beginnings and the start of a new chapter once their ulcer heals. The stories do not narrate in a manner that signifies closure or freedom from the past life of drug use: that episode in life is lived not necessarily finished or forgotten.

#### **5.4.2 Vulnerability and resilience: the two faces of stigma**

Taking Goffman’s stance of appreciating the ordinary yet intricately complex face of stigma, the findings have demonstrated a place for narrative inquiry as a way to give voice the physical and social representation of the wounded drug user. Modern means of representation, such as mass media, can falsely portray the drug user population and deceptively frame the dominant discourse that society holds in regard to this marginalised group of individuals. The stereotypical representation of drug users’ face: sunken eyes, lifeless skin, emaciation. This identity is deviant to what is perceived normal society and supports Giddens theory (1991) of the duality of structure: when a population fails to uphold the regulations and rules of conventional society, it is marginalised as a way to distance from what is uncomfortable and unfamiliar. However, the findings have the potential to connect on a greater level than deviance; by thinking of how Goffman utilised the ordinary in stigma, the narratives can be directed to restore the gap of the duality of structure. Acknowledging the narratives of these marginalised people, the findings have embodied the complex nature of drug stigma and challenged it by humanising and normalising it. The findings depict the son, mother, daughter, husband and wife. Their stories demonstrate normality in daily activity, personal characteristics and attributes; their narratives portray real pain yet resilience in the face of adversity.

Ultimately the narrative portrayal of these people defies societal stigma by reaching a personal common ground within the individual: the person behind the story.

This study does not dispute the socioeconomic vulnerability of illicit drug use: unemployment, homelessness, mental health and incarceration. The study wishes to focus on the self-perceived social representation of drug users who have leg ulcers. The imagery associated with the physical features of illicit drug use and leg ulceration conjures distinct characteristics. The physical picture of a wounded drug user with malodorous, leaking ulcers and the display of their unpredictable behaviour has the potential to create a preconceived notion of chaos, self-neglect and defiance. The perception of a wounded drug user is often perceived by healthcare professionals as deviant to the norm, apart from the general population of patients presenting with a leg ulcer. This narrative inquiry has the potential to change the way that society sees this group of people. The study proposes an alternative view to the one commonly presented in the current literature with the potential implication of altering how we perceive and feel about this group of people. It portrays another side of the disorder and challenges our stereotyped ideas about the character of a typical drug user with a leg ulcer, through their words of resilience, honesty and selflessness.

*“My life changed after my husband was diagnosed with cancer in his lungs and I had to take control over my life to help him...The first thing I did was I bought a litre of methadone and started taking to stop take heroin...” (Isla’s diary)*

The findings also focus on the self - preservation of the person through depiction of their narrative: the story of struggle, pain and survival.

Goffman (1963) seminal work supports the narrative findings of this study. From the physical changes and malformation of leg ulcers to the admission of spoiled character from drug use, the participants have embraced this narrative stigma in terms of how they described themselves. The findings clearly indicate participants as discredited in their uniqueness of having leg ulcers; they do assume that others, mainly health professionals, treated them differently because of their background of drug misuse. Participants believed that their physical characteristics and background of drug misuse and leg ulceration were identifiable and, as a consequence of this, being discredited. There is also a great deal of self-control and concealment as participants hide the fact that they have a leg ulcer from family in an attempt to spare them from this burden; this act of resilience and self-control again demonstrates the strength of the individual character and where their priorities were. They did use

strategies to deflect from their differences; the use of humour and artistic expression was a way in which participants attempted to overcome the emotional barriers their stories described. The narratives do not conceal the reality of the life lived.

The findings clearly demonstrate that participants experienced stigma in the form of barriers in attitudes, practice and empathy when receiving care for their leg ulcer. There is both felt and enacted stigma presenting in a cyclical and destructive pattern. Participants blamed themselves for the development of their drug-related ulcers; they perceived the same blame from health practitioners and when in contact the enhanced feelings of blame exacerbated the perceived stigma.

The findings presented in this study confirm that IDUs living with leg ulceration experience stigma in all forms: oppression, deviance and vulnerability (Scambler, 2009). The narratives have demonstrated that the experience IDUs have regarding health care professionals directly affects the service they receive for their leg ulcer care. It is important to note that, for those participants who were in regular contact with leg ulcer services and had established continuous care, there was an overall improvement in their experience, healing and positive future perspectives. These examples of good practice need to be modelled and shared out to other organisations as a means to deliver the appropriate care to PWID who live with leg ulceration.

In order to understand the stigma endured by this population in day-to-day life and in clinical practice, the implications emerging from the findings must be translated across a number of disciplines in health and social care. Only with fully integrated services that “talk”, can a real and sustainable change be achieved. It struck me that participants who had experienced felt or enacted stigma relating to their drug use and/or leg ulceration had described experiences of a hierarchical or imbalanced power relations with their practitioner. This misuse of authority exerted by health care professionals resulted in an unequal and unbalanced relationship between the patient and the clinician. The findings clearly demonstrate that people who inject drugs had directly encountered prejudice in practice either in words, actions or both. In a modern age of equality for all genres of humanity, age, sex and ethnicity, it is not acceptable that the most vulnerable individual may still endure the margins of society and the prejudice and discrimination associated to their medical condition of drug addiction. The uncomfortable hierarchical imbalance of relations affecting the minority of those who inflict or play a part in enacted stigma needs to be addressed. There is a lack of epidemiological studies identifying the real prevalence of this population that experience stigma; this study recommends that further research

should be conducted to understand the enormity and scale of this issue and address in full, the extent and level to which stigma still exists in clinical practice. Aligned to this, the findings argue that the population of drug users are seen as vulnerable in health care practice and therefore should be a “safeguarded” and protected population within the health system. With this in mind, the study recommends the establishment of appropriate governance routes for those who experience the dynamics of stigma in practice to ensure issues are addressed, reported; ultimately a culture of zero tolerance in practice should be cultivated and established in the behaviours and values of health and social care organisations.

On a personal note, I have worked in an outreach capacity with people who have injected drugs and have an associated wound for many years. I engage with various health professionals from doctors, key workers, employment advisors and nurses. One of the reasons for successful practices engaging with this clientele is the abolition of hierarchy and “powerplay” between the clinicians and the patients we serve. We exist to care and improve life for those in need and this mind-set has created a unique environment to work in: one built on equality, balance and respect between clinician and practitioner and service users. Ultimately we are the same, struggling for the common ground that, once established, results in engagement and improved service user experience. This is a continuous negotiation and learning area that requires to reflect both individually as a clinician and together as a practice.

It could be argued that this uncomfortable relationship between clinician and patient does not exist; however, in the words and experience of the respondents, it is perceived as true, on various levels and continues to impact negatively on their quality of life.

To confront this often subconsciously hidden and uncomfortable reality, I advocate the need of a large-scale campaign involving all disciplines and including service users: a multi-disciplinary round table discussion, co-designing services and improving care together.

The central premise for this is creating and sustaining awareness of the lives of these marginalised people; this should not be exclusive to the wound care field and should be inclusive of all specialities who interact and care for these people. The real face of stigma is misunderstanding, fear and ignorance. Raising awareness would challenge these negative prejudices around people who inject drugs. The narrative findings emerging from this study have the potential to support a campaign to emphasise the real person behind drug use by discovering the common ground in our lives as one people. Practitioners and service-providers should learn from the

lived experience of IDUs with leg ulceration to challenge their current practice, engage with this clientele and standardise service provision for this group of people.

It is important that the individual suffering and the associated stigma remain at the forefront of a campaign for holistic health care for IDUs following the footsteps of current public awareness projects in the area of mental health. The importance lies with the individual narrative and not the process by which it is expressed. By highlighting the uniqueness of each person, momentum can be maintained for clinical groups that work consistently with this clientele. There are a number of levels this can be instigated.

Throughout this study I have been clinically involved with local services delivering such care and I have implemented and disseminated learning in my clinical practice. The findings present a group of people both vulnerable and resilient in the face of their enacted and felt stigma. As professionals, we must be able to work and empathise with this group of people.

Crucially we must nurture and respect the resilience while promoting independence. We should work together to develop a wound plan that best suits their clinical needs and lifestyle while acknowledging their vulnerability and safeguarding the way we provide care. The narratives have given us a glimpse of how PWID continue to celebrate or liberate their voice and identity through narrative means. Again, the narrative has allowed us to see another side to the person.

### **5.5 The artistic narrative: expressions of self: talent, humour and language**

The manner in which IDUs chose to depict their experience of living with a leg ulcer included both descriptive and artistic means. Emily chose to draw and colour her leg ulcer with remarkable skill and accuracy in her diary (Appendix 13). The level of details and use of colour demonstrated how well Emily knew her ulcer and that she was comfortable in illustrating it fully showing the extent of the wound area. The picture was exact in its content, with almost perfect anatomical representation of the wounds down to the different types of tissues within the wound bed. Emily knew her leg ulcer in detail. Her drawing took time and attention and demonstrated the level of commitment Emily had in sharing her story. She went on to expand on this by narrating a poem in her diary which she had composed whilst in prison entitled "*Mr. Crack*". The raw, emotive detail of this narrative demonstrated the struggles Emily faced with her drug use at this time. The strong language and way in which Emily now confidently shared this in her journey of living with a leg ulcer demonstrated that

these events were in the past and she was ready to share her memories of this part of her life with the outer world. Emily was able to embrace her narrative journey as described in her interview.

*“Yeah, yeah I feel happy to do it. I thought it would help myself sort of understand why and you know... why I’m in the situation I am....it’s very interesting to know how I feel and how to change things, to make things better”.*

Poetic inquiry is an elusive, exceedingly personal process as the writer moves through a series of thoughts, emotions and images to then shaping these into words on a page. In qualitative research the recognition and sharing of this form of inquiry is essential to add breadth and depth to life stories (Butler-Kisber, 2010). Arts-based research such as poetry, offers new and complementary information about cultures and objects of study, with poetic processes seen as both the tools of discovering the emotion behind the phenomenon and a unique way in which to report research (Brady, 2009). The telling of stories that bear witness to human suffering and experience calls for methods that move researchers to consider multifaceted ways to investigate the science and art behind the person and the illness (Viva Davis Halifax & Mitchell, 2013).

This form of inquiry was not considered at the onset of the study. The findings demonstrate that poetic inquiry can be used to complement the complex emotions and capture the realities of the lived experience. The narrative arts, including illustration, can allow voices from marginalised populations to be seen and heard and in some instances, where populations are hard to reach such as IDUs, they may be preferable to conventional methods of social science writing. Poems and drawings can create a felt sense of the phenomenon through understanding and empathy in comparison to a detached cognitive understanding (Carroll et al., 2011).

Lucinda also chose to draw her ulcerated legs in her diary (Appendix 14) and she described them

*“Ulcers starting to fizz because I know that the dressings need to be changed....Looked like I had been bitten by a shark!”*

The use of imagery narration is a unique contribution to the evidence of experience of leg ulceration in the IDU population. This is a unique contribution into the understanding of the value of images in the life of the wounded. Spoken or written language may be imperfect media to fully represent everyone’s holistic life experience and visual methods such as the arts facilitate communication through different modes. It also adds another layer of emotion to the story as a whole and

portrays a visual voice to the life lived. Together with the written narrative, this enhances credibility and accentuates openness and humility to the person behind the narrative (Alerby & Bergmark, 2012). There are limits to using visual data alone; however, in cases such as the wounded storyteller they are a valuable contribution to the written story of an open wound.

Lucinda also uses descriptors, some negative to depict how her ulcers felt and its impact on her life.

*“Left leg “AWFUL”. Having no proper dressings has really impacted on me! Not looking forward to next 2 weeks until I see the nurse again. Leg (left) stiff, fizzing, burning, hot poker.”*

Language was an important instrument for Lucinda and many of the other participants. Similar to Emily’s narrative Lucinda embraced the diary as a way to portray her leg ulcer journey as she was at a point in her life where she felt confident and comfortable to do so. They used descriptors to bring life and meaning to the words.

The use of metaphors and rich descriptors is recurrent theme throughout the narratives as the participants attempt to provide an insight into their lives in more than just words. Users have been shown to use rich metaphors to tell *Stories of Hell and Healing* to portray their suffering (Fixsen & Ridge, 2017). Metaphors’ analysis has been used to understand withdrawal symptoms of benzodiazepines proving that a person-centred perspective has the potential to influence and change attitudes to complex health populations such as IDUs. The focus on the model of patient experience can lead to the implementation of innovative treatments and the alignment of services to meet the everyday needs of the population (Fixsen & Ridge, 2017). Metaphors, in this case, were used to describe the complex relationship between the participant and their leg ulcer, to the extent that in some instances the leg ulcer takes on an identity and importance of its own.

Oliver’s diary and interview revealed the double-sided relationship with his leg and used this relationship to convey how he felt about his leg ulcer.

*“I hate the constant ritual of dressing changes. Enough is enough now, just want it over....Sometimes just want my leg of, still would miss it like mad though. How mad is that.”*

*“You don’t think about it on a daily basis you just got so used to it being part of my life so it might be strange not actually having to have it dressed...really weird kinda bitter sweet”*

Humour is used throughout the narratives as a way to release tension for both storyteller and listener. Daniel used humour and metaphors to detract from the seriousness of his drug use. His description of himself being a “giro junkie” depicts the humorous scene of his current drug use as a social habit, one he is in control of and can describe in a casual manner. Throughout his interview the use of humour and physical movement and restlessness releases the tension of what is being described within the narrative, making the story easier to listen and reducing the emotional impact on the listener.

## **5.6 The narrative continues**

This chapter has discussed a number of themes within the narratives of living with leg ulceration from the perspective of people who have injected drugs. These narratives represent a snapshot at a particular time in the life of the storytellers and what has been written or told at that moment could differ at another time and place. People who live with leg ulceration have complex thinking processes about themselves and those around them. We must try to put ourselves in their shoes if we aim to ever really understand the daily challenges they encounter. It is of course impossible to completely identify with another way of life; however, narrative inquiry is an effective method for health practitioners and scientists to attempt rediscovering the people we treat and explore. The concluding section will present a summary of the design, limitations of the study with recommendations for further research in practice, closing with a personal annotation.

The narrative findings reinforce the conclusions that emerged from the literature review. The narratives confirm the divisions and gap between generalist health care and the more desirable holistic service provision for people who inject drugs living with leg ulceration. The stories presented in this study highlight the need for health research on the daily lived experience living with a leg ulcer; the real voice of people who inject drugs living with leg ulceration is not heard within qualitative studies from a narrative standpoint. For this reason, referring back to Giddens work on duality of structure, the narratives demonstrate a breakdown in the engagement of this population living with wounds in health care research. They are deviant therefore misunderstood, marginalised and as a result feared. Yet, their narratives defy this deviance by validating their wish to engage in a study which would liberate their voice and potentially establish a humanitarian common ground that humanises the life, the person in all the richness and complexities that make us individuals. This

study depicts areas of practice in the field of specialist wound care that have proven successful in terms of experience, satisfaction and healing. Health researchers can look to these areas of good practice to explore in further depth wound care in this clientele. There is a need for more in-depth studies to assess the management of wound pain for people who inject drugs as the findings clearly demonstrate a concerning unmet need with significant impact on the physical and mental health and wellbeing of people who inject drugs. Furthermore, the findings advocate the necessity for more education on wound management in this population, both in general health care and specialist services involving all disciplines. The integration of education and practical care of this patient group would ensure that all health care workers would be equipped to manage a leg ulcer in whatever context this was presented. The narratives demonstrate there is a level of work needed to build relationships both in clinical practice, academic and research to ensure this population living with wounds is included, to insure their future within the health service is secured. This study is a good example of integration and building relationships from a clinical, academic, research perspective and the value of listening to people on the front line.

## **5.7 Summary of conclusion**

This study has explored the experience of injecting drug users living with leg ulceration. The philosophical concept to interpret the life of IDUs by process of narrative inquiry used qualitative methods of diaries and semi-structured interviews. The description of the life lived and voiced by those affected in an undiluted manner was central to the design of this study, providing a unique contribution to current evidence. The insight on the identity of the person behind the illness has provided clinicians with a novel perspective that may potentially constitute a paradigm shift in the clinical practice, revolutionising the way health care providers approach and engage with this vulnerable patient group. The critical discussion on stigma as a detriment to the health of IDUs showed how health practitioners have played a role in their felt stigma by exacerbating the enacted stigma of the individual. As a result, participants often rejected the possibility of further care due to the fear of prejudice and ended up self-treating their ulcers. Consequently, this led to delayed wound healing that greatly affected their quality of life.

Participants embraced the study as an opportunity to portray their voice and tell their life story to someone they trusted. The relationship between the nurse-researcher

and participants was an important element which facilitated data collection. The original research questions and aims are answered and addressed to examine how this study has made a contribution to knowledge.

### **5.7.1 Research questions and aims: implications for practice**

*What are the experiences of injecting drug users living with leg ulceration?*

The study has fundamentally addressed this question from a number of perspectives. Firstly, from the accounts of participants it is clear that their leg ulcers cause a great deal of pain and suffering and how this may continue for many years. The experience is personal, both physical and emotional, as participants related their feelings to practical issues of having a wound such as clothing, relationships, discomfort and mobility. These experiences are not dissimilar to the general population with leg ulceration; however, the manner and emotion in which the experience was portrayed and linked to the identity of the individual was unique.

Secondly, the broader sociological implications of the study include training and education for clinicians and health care providers to ensure people who have a leg ulcer, regardless of circumstances, can access safe, competent practice in a professional and caring environment. It is not enough to treat a condition in isolation of the person and overall the findings indicated that the majority of clinicians do not have the skills to address both substance misuse and wound care in this population. Health carers, policy makers and academic institutions must acknowledge this shortfall and work toward inclusive ways of integrating wound management into services for this patient cohort. Previous studies demonstrated the massive challenges ahead with drug use in the UK: tackling the supply of drugs and crime, drug therapy and reintegration. There is also a growing burden of chronic wounds, including leg ulceration, and a shortage of general nursing clinicians; therefore, timing is pertinent to address the skill mix of our generalists and upskill mental health, substance misuse and social care teams. The study has highlighted the lack of a clear clinical pathway for IDUs with leg ulceration showing failure in diagnosing the aetiology of the wound and providing the appropriate treatment. In addition, the findings have reported the discrimination and negative experiences of the participants when in contact with health care professionals. The majority came across specialist wound care by chance and as a result many of them had self-treated their leg ulcer for years. For those who attended, the narratives addressed the experience of IDUs reviewed in wound clinics.

**Aims:**

To explore the experiences of IDUs attending leg ulcer clinics, from a narrative perspective.

Participants did not question whether their leg ulcer treatment should be provided in primary or secondary care. The narrative emphasised that they were willing to travel for the positive experience they had, especially when they visibly experienced clinical improvements and wound healing; some walked up to 40min to have their leg dressing changed. There was an awareness of the lack of resources for clinics that could not provide chronic leg ulcer management. IDUs that attended their generalist GP reported negative encounters and prejudice as well as inadequate wound healing. For those who attended specialist outreach or tissue viability clinics where specialist wound care was provided, the overall experience was positive. All the participants in this design at the time of data collection reported being in contact with specialist services and having compression bandaging therapy for their venous leg ulcer. This had a direct impact on their care, ulcer healing and wellbeing. All of the participants described a positive experience and improvement in their leg ulcer, some of the ulcers had healed.

To examine IDUs experiences of having a leg ulcer and how this impacts on their quality of life.

The impact leg ulceration has on this group of people is substantial and exacerbates feelings of stigma already internalised from their drug use. The metaphors and rich descriptors used to portray how their ulcers made them feel was a glimpse into the magnitude of suffering and isolation felt while living with these wounds. The narratives revealed that the shame and guilt originated from their previous drug use and provoked the self-blame for their leg ulcer. The life experience of IDUs living with an untreated leg ulcer is poor and has been shown to inhibit detrimental feelings of stigma. This, in addition to poor encounters with health care practitioners, has been shown to intensify these feelings. As participants often concealed their ulcers from friends and family so as not to upset them, their silence added to their loneliness that in turn affected their daily life and their feelings.

### **Specific questions and aims:**

How do IDUs describe their history and experience of developing and living with a drug induced venous leg ulcer?

From the beginning participants linked their drug use to the development of their leg ulcer and they provided detailed histories on how this occurred and their past lives of drug addiction. Reliving these experiences coincided with the feelings of blame and the perception they had self-inflicted these wounds. Many felt they deserved to suffer their wounds because of their drug use. The narratives surrounding the history of drug use are detailed and at times harrowing, yet participants use art, humour and talent to establish resilience amongst the chaos of their drug past.

How do they describe interactions with health care practitioners and services?

The majority of participants described stigma at one point when they had encountered health care services and practitioners. From their perspective, they blame their history of illicit drug use as the reason for this and prejudice as a direct result. Participants receiving appropriate specialist care reported a good relationship; again this directly impacted on their leg ulcer experience and in their perceived healing outcomes.

What are the implications on current clinical guidance and training for health care professionals who look after IDUs with leg ulceration?

Current UK leg ulcer guidance is outdated and needs to be reviewed in line with changes to the populations with lower limb complaints. The National Institute for Health and Care Excellence (NICE, 2016) have revised the venous leg ulcer and compression guidance based on the report of experts in lower limb care (Royal College of Nursing, RCN, 2006; Scottish Intercollegiate Guidelines Network, SIGN, 2010). This guidance should include the expertise of medical and surgical colleagues dealing with all different categories of lower limb ulcer patients and not exclusive to the older adult.

PHE (2018) has encouraged local commissioners, providers and professionals to invest in drug and alcohol treatment services; well-funded services are seen as value for money in improving health of the individual and supporting recovery. This recent presentation failed to highlight leg ulceration or wound care as a problem associated with injecting drug usage, simply mentioning “poor vein health in injectors”. The narrative of IDUs living with leg ulceration can be used to demonstrate the clinical

and emotional needs of injecting drug users that live with leg ulceration with the view to reform the current social and political agenda on this topic

Nursing as a profession has advanced significantly in recent years with acquired skills in assessing and managing complex vascular patients such as IDUs with leg ulceration; current guidance must reflect that autonomy and experience. With new changes to the nursing profession, including the introduction of the new role as nurse associate, we must continue to ensure that these skills are safely disseminated throughout the nursing profession to prioritise and respect people, practise effectively, preserve safety and promote professionalism and trust (Nursing & Midwifery Council, 2015).

Training should be provided for all generalists on how to manage the clinical requirements and emotional needs of vulnerable people who inject drugs in different, often complex and hostile, settings. Wound care education needs to be addressed for the specific needs of IDUs and co-designed with patients for maximum benefit.

To examine IDUs experiences of having leg ulceration and how this impacts on their quality of life and recovery from addiction.

Most of the participants were in the recovery stage of their addiction and, although admittedly some still used illicit substances, they did not present in the acute phase of their drug use and none reported actively injecting. In terms of impact, the majority identified their leg ulcer as a clear link to their past drug use and the emotional ties of their addiction. Participants revealed that their leg ulcer was a bleak reminder of that time in their lives. They looked forward to their ulcer healing and the beginning of a new life although some admitted the fear of no longer having a leg ulcer.

To explore how clinicians / health professionals work with IDUs in leg ulcer clinics.

The findings have demonstrated that participants who were in contact with specialist services, have perceived positive experiences, better healing outcomes and overall a better care than the ones who received care from general practice.

To explore what prompts IDUs to seek help for their leg ulcer care.

The narratives acknowledged that if IDUs have encountered stigma in relation to their leg ulcer care, they withdraw from that service at the detriment of their own leg ulcer. Participants reported dressing their ulcer for long periods of time without intervention rather than revisit that experience. Frequently they come back to clinical practice when their leg ulcer has deteriorated or they are unwell. The possibility to be

referred to specialist services is often “by chance” and IDUs reported missed opportunity and regret at not being seen earlier once they realised their ulcers were healing. Importantly, if these people have had a poor experience from an encounter with a health care practitioner they would not attend at the risk of a similar experience, regardless of their ulcer.

To explore IDUs route of access to leg ulcer clinics.

The main access routes for IDUs to wound treatment in primary care are general health clinics that run alongside substance misuse treatment centres. In North London particularly, these are a limited resource. Although not accessed for this study, homeless services are known to provide wound care for the street homeless. In secondary care the main point of referral for IDUs is A&E when they experience a complication of their leg ulcer or other vascular urgency; the vascular surgical team will refer them to the tissue viability specialist nursing team for leg ulcer assessment and dressing. There was no consistent pathway highlighted in the narratives.

The findings have raised important issues about the delivery of care and service experience for IDUs and highlighted successes, challenges and potential gaps in practice.

### **5.7.2 Summary benefits of the study for practice and theory**

The study has demonstrated that narrative inquiry is a unique and privileged opportunity to research and portray the lives of injecting drug users living with leg ulceration. It has also proved beneficial to the participants themselves as they reflected on their life lived and how far they had come on their journey. The diary method proved a success and all participants completed the four week data collection. The semi-structured interview reinforced the story in a trusting and open manner with the nurse-researcher.

IDUs embraced the methodology and this form of inquiry providing an exclusive contribution to research and practice.

The study offers an account of the practical details required to undertake similar work but also a valuable insight for practitioners on the importance of dedicating time to listen to the person we treat in everyday health care. For this group of vulnerable people building and maintaining a trustful relationship is an essential part of their treatment.

People who have injected drugs and live with leg ulceration have complex lives due to their health and social care needs and the stigma associated with their wounds and illicit drug use. The ulcers that mark their legs are a constant reminder of their drug use and for some the last sign of their past drug addiction. The stigma that surrounds these people's lives does have debilitating and life limiting consequences and often results in a revolving cycle of shame, grief and pain. By portraying the story of the person and not focusing solely on the drug use, participants provided us, in their own words, an insight into their lives past, present and future. Their revelations brought a deeper understanding, and a novel methodology was used to interpret their voice.

### **5.8 Limitations of the study**

A number of study limitations must be acknowledged. Researching this clientele as a nurse-researcher and recruiting NHS patients created a number of practical considerations which included a prolonged period of time to process all the relevant regulatory material and gain ethics approval. It took over 12 months to successfully complete the IRAS form and submit to the ethics committee. Fundamentally, accessing NHS service users was central to the design and facilitated the unique insight to their lifestyle and the current service provision provided by the public health sector. There was no conflict of interest with the design and the researcher successfully ensured purity of the data from a nurse-researcher perspective.

The sample selected was known to me in a clinical capacity; as participants were considered hard to reach, this was essential given the resources for this study and the uncertainty of recruitment uptake. The sample was relatively small with ten participants successfully completing data collection; it is difficult to establish if a larger sample would have provided more meaningful analysis as the participants and gatekeepers required support and contact throughout the study. A larger sample would have required additional resources to capture the data and also support the participants throughout the experience while maintaining rapport which was an essential component of the study. Given the complexity of the participants and the three sites involved with recruitment, the sample of ten was considered adequate to address the research question.

The design methodology proved to be successful; having reviewed the artistic data of illustrations and poetry, visual data collection could have been included for example collecting photography of life events, capturing snapshots of their living with

leg ulceration; it was not possible to deduce this form of inquiry until after data collection.

As lead nurse for tissue viability, I had contact with participants before and after the study due to my expertise in this field. There was a geographical limitation, recruiting only within my clinical borough of London. Furthermore, the recruitment did not involve other service areas such as homeless teams, other treatment facilities and prisons.

## **5.9 Recommendations**

### **5.9.1 Education and practice**

The literature review identified a clear gap, both in the generalist and health care evidence based practice regarding the holistic care of wounds in people who inject drugs. The findings have confirmed the dramatic consequences of this gap in real life by narrating poor experiences when encountering general health care practitioners resulting in patients' disengagement and poor leg ulcer treatment compliance. Participants also identified the negative reverberations of these encounters on their own felt stigma, ultimately affecting their desire to seek help for their leg ulcer healing. It could be argued that the gap in translational clinical research to bridge the social and health care needs in the IDU population has contributed to inadequate management of this patient group. The poor-quality and often conflicting evidence supporting wound care in the drug user population is geographically limited to a UK perspective and mainly limited to the nursing literature. The narrative perspective of IDUs living with wounds must be acknowledged in the medical and sociological fields with a view to create higher level of scientific evidence and stronger recommendations support the clinical care of these individuals. It is simply inadequate to think of this as a "nursing" issue; in order to gain engagement and ultimately treat this group of people, the medical field must not only appreciate the narrative life of these patients but also embrace narrative inquiry as a means to understand and treat the patients fully and wholeheartedly. The foundations of engagement and success with this clientele is through the fundamentals of relationships, built on respect and trust.

The study has identified the need for a clear clinical pathway for injecting drug users living with leg ulceration to access care for their wound ideally close to their residence. This should involve all members of the multi-disciplinary team who should work together to establish local guidance and protocol for the care of these patients. This, in turn, should be communicated to local commissioners who can invest and

establish services, co-designed with patients. Ideally patients should be managed in primary care; however, there needs to be an integrated approach modelled to ensure that the patients' preference for the place of treatment matches with the availability of appropriate wound-care skills. The study advocates for an educational package for all clinicians in the acute and community settings, across all disciplines, regarding basic wound management with access to advanced skills training and clinical links to affordable and accessible training. This should be updated regularly to ensure care is based on best available evidence.

When meeting with this patient group, it is important to acknowledge and understand their true story, and not be biased by their drug history. If time does not permit, for instance in the event of an medical urgency, it is fundamental to establish the relationship, gain trust and respect and assure the person that the interest lies with them as people and not on their medical history of illicit drug use. For long term patients, particularly those with chronic conditions such as leg ulceration, BBVs and diabetes, diaries offer a useful method to maintain the relationship with patients with the potential to identify physical symptoms or anxieties they may be experiencing.

### **5.9.2 Policy recommendations**

The Five-Year Forward View (NHS England, 2014; 2017a) in line with the NHS (NHS England, 2017b) vision is that with the right support and access to general wound clinics and specialist input IDUs could be able to self-manage their wound care in the future. This may be possible in line with the provided recommendations reported. If patients feel that self-care is the best option then this opportunity should be discussed in a supportive manner. There is a role for voluntary organisations and charities who work with IDUs to be trained in wound management. There is also the possibility to develop a prevention programme and reduce the harm associated with injecting and the development of wounds. For those that have been diagnosed with venous disease of the lower limb from injecting, prolonged compression therapy after wound healing has the potential to prevent reoccurrence. It should be acknowledged and included in the general health assessment that chronic venous ulceration can be prevented in this specific population with regular follow-up and health promotion advice (Nelson & Bell-Syer, 2014; O'Meara et al. 2012)

PHE (2018) has encouraged investment in services supporting the treatment and recovery of drug users with, as yet, no specific focus on wound care. Recent data from a major London hospital has shown an increase in skin, soft tissue, and vascular infections (SSTVI) with IDUs-related admissions accounting for 58% of the total (Lewer et al., 2017). Priority should also be given to achieve a more holistic approach to wound care by involving specialist tissue viability teams with a view to train a wide range of health care professionals in the prevention and treatment of chronic venous leg ulcers and general wound care.

This work could be fundamental to scientists who wish to reach a deeper understanding in this group of people; the methodology could be used to research other hard-to-reach groups. Narrative inquiry has the ability to be used across a number of disciplines to portray the voice of those considered marginalised. It also has the ability to challenge conventional social stereotypes and address potential societal stigmas.

### **5.9.3 Conclusion and personal annotation**

The study has depicted a moment in history to portray the experience of injecting drug users living with leg ulceration in London. The voice of the wounded storyteller has real significance in the social and health care world today as we work towards reducing the impact that drugs have on the physical and psychosocial well-being of our population. The condition of leg ulceration remains inevitable while people continue to inject drugs; therefore, the prevention and treatment of wound care needs to be included in local GP practices and outpatient clinics and awareness raised on broader levels, by including commissioning specialist services and educating the workforce.

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# MANAGING LEG ULCERATION IN INTRAVENOUS DRUG USERS

Jemell Geraghty explains how emergency department nurses can manage leg ulceration in patients who have injected in the lower limbs

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## Abstract

Chronic venous leg ulceration is a long-term condition commonly associated with lower-limb injecting and chronic venous hypertension caused by collapsed veins, incompetent valves, deep vein thrombosis and reflux. It is not usually a medical emergency, but intravenous (IV) drug users with leg ulcers can attend emergency departments (EDs) with a different primary complaint such as pain or because they cannot access local primary care or voluntary services. Leg ulceration might then be identified during history taking, so it is important that ED nurses know how to assess and manage these wounds. This article explains how to assess and manage chronic venous leg ulcers in patients with a history of IV drug use, and highlights the importance of referral to specialist services when required, and to local primary care or voluntary services, before discharge to prevent admission and re-attendance.

## Keywords

leg ulceration, substance misuse, wound care, Doppler assessment

MANAGING LEG ulceration in emergency departments (EDs) can be time consuming and challenging for nursing staff. A proportion of non-urgent care, including bandaging and wound dressing, takes place in EDs when it could be managed in general practice or community settings (Lowy *et al* 1994). However, for some patients with leg ulceration, particularly those without

residence or no allocated GP, EDs are a point of contact for dressing changes. For intravenous (IV) drug users, leg ulceration is unlikely to be their primary complaint but it can be a chronic condition that should be addressed as part of holistic nursing assessment.

Regularly injecting IV drugs into the lower extremities can lead to chronic venous hypertension, abscesses, wound infections and pseudo-aneurysms in the groin, which often require urgent vascular intervention and hospital admission (Louria *et al* 1967, Pieper *et al* 2009). Chronic venous leg ulceration (Figures 1 and 2, page 18), however, is rarely an urgent clinical scenario, and IV drug users with leg ulcers are more likely to attend EDs for pain management or because they cannot access local homeless teams, outreach services or specialist GP centres for mental health care, help with their substance misuse or dressing changes.

ED clinicians must be able to manage these patients' wounds appropriately, prevent admission if possible and refer on for wound-care follow up to prevent re-attendance. Recognising the clinical signs of local wound infection and understanding general wound management are essential skills for managing this client group, and enable clinicians to plan, implement and evaluate care competently (Cook 2012).

Chronic leg ulceration is not an emergency unless the underlying aetiology is compromised, for example, in patients with deep vein thrombosis, if there is evidence of infection or if revascularisation is required because of critical lower-limb ischaemia, pseudo-aneurysm



or lower-limb abscesses. A thorough assessment in terms of history, duration and cause will help identify these conditions and support accurate treatment and referral pathways.

Managing leg ulceration in IV drug users can be challenging for ED staff in terms of delivering timely and effective wound care and managing pain, organising appropriate aftercare and preventing admission. Generally, patients with a history of illicit substance misuse do not want to be admitted to hospital as this would interfere with their routines and frequented environments as well as any rehabilitation or therapy programmes they attend.

### Prevalence of leg ulceration

Leg ulceration is defined as a ‘loss of skin below the knee on the leg or foot which takes more than six weeks to heal’ (Dale *et al* 1983). The main types of lower extremity ulcers are venous, arterial, mixed venous and arterial, rheumatoid, diabetic and, rarely, malignant (Royal College of Nursing 2000).

Venous ulcers make up the majority with up to 80% caused by venous disease, while arterial pathologies account for between 10% and 25% and can coexist with venous disease (Valencia *et al* 2001).

The incidence of arterial insufficiency is likely to increase with age and lifestyle factors such as smoking and heart disease (Valencia *et al* 2001).



**Figure 1** Examples of leg ulceration in the intravenous drug user population



**Figure 2** Examples of leg ulceration in the intravenous drug user population

Most venous leg ulceration results from incompetence of the valves of the superficial or perforating veins, although almost half have evidence of previous venous thrombosis (Sarkar and Ballantyne 2000).

Leg ulceration occurs mainly in older adults, and this is particularly true of venous leg ulceration, which is most common in people aged 65 and over (Margolis *et al* 2002). However, IV drug users with leg ulcers are generally younger, often between late twenties and early fifties.

Until recently, the prevalence of skin problems, particularly leg ulceration, in this patient group was unknown. However, Coull *et al* (2014) conducted a quantitative study on the prevalence of skin problems and leg ulceration in young drug users in Glasgow and found that, of 200 participants aged between 21 and 44 with a history of current or previous injecting, 60% had experienced skin problems such as abscesses, lumps and track marks, and 15% had leg ulcers.

### Assessment

Wound assessment in EDs requires a more prompt inquiry approach than other areas of acute care. Medical histories are often unknown, time is restricted and patients’ physical and emotional condition can be problematic in terms of establishing trust and gaining full histories.

Nurses in emergency care often have limited information to work with, so it is vital to undertake

**Figure 3** Formula for calculating ankle brachial pressure index

$$\frac{\text{Ankle systolic pressure}}{\text{Brachial systolic pressure}} = \text{Ankle brachial pressure index}$$

**Box 1 Ankle brachial pressure index values and clinical interpretations**

- ≥ 1.0 Within the 'normal' range for compression bandaging to be used
- ≥ 0.8 Excludes significant arterial disease. Compression is indicated
- < 0.8 Indicates arterial disease. Reduce compression bandaging and request further vascular review, according to local protocol
- < 0.5 Contraindicates compression. Urgent vascular referral is required, according to local protocol

(Worboys 2006)

head-to-toe examinations while actively listening to patients.

It can be difficult to establish the exact aetiology of leg ulcers in EDs because of time pressures and the complexity of wounds, but it is good practice in each case to ensure that a Doppler ultrasound assessment is carried out, in the ED or at outpatients, to determine if the ulcer is predominately venous or arterial.

A Doppler assessment involves use of a basic vascular device to listen to peripheral arterial sounds and measure the ratio between the systolic pressure of the upper limb (brachial systolic pressure) and that of the lower limb at ankle level (ankle systolic pressure). The latter is divided by the former to give the ankle brachial pressure index (ABPI) (Dealey 2012) (Figure 3).

Up to two pedal pressures are needed for the ankle systolic pressure, the highest of the two is then used for the right and the left leg. The brachial pressure is taken on both arms, with the highest used as the main brachial systolic pressure.

All other pedal pulses should be listened to using a hand-held Doppler and the signal or waveform should be identified, for example as triphasic, biphasic or monophasic.

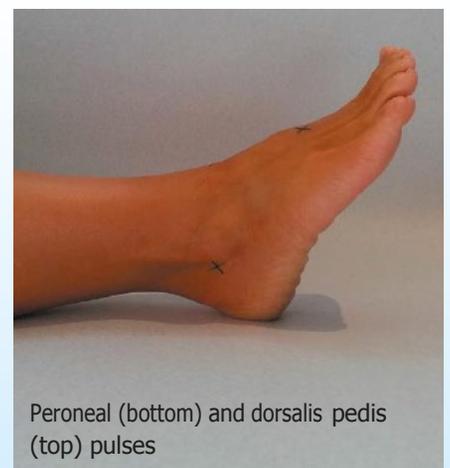
The ABPI should be considered in the context of each clinical presentation and thorough patient assessment. General interpretations of ABPI results are listed in Box 1 in relation to compression bandaging, the gold-standard specialist treatment for treating and healing venous leg ulceration, controlling oedema and preventing recurrence. Compression bandaging, which must be carried out by competent practitioners, supports venous return in the foot and calf-muscle pump by consistently delivering graduated pressure, at around 40mmHg at the ankle in the UK, which increases venous blood flow up the leg and supports fluid drainage in the venous and lymphatic systems (Moffat *et al* 2007, Anderson and Smith 2014).

If patients have a suspected vascular injury or are at high risk of thrombosis, medical or surgical teams will often request a venous and/or arterial lower limb duplex, involving a non-invasive diagnostic device that provides ultrasound images and Doppler signals to assess blood-vessel morphology, as well as flow velocity and direction.

It is good practice for ED nurses to be familiar with the vessels and pulses of the lower limb and foot as clinical examination of these is routinely used by specialist nurses and doctors. The points at which to assess the pedal pulses are shown in Figure 4. ED nurses should practise locating all pedal pulses and palpation, although often the dorsalis pedis and posterior tibial pulses are commonly assessed.

Once circulation is judged to be clinically sound with no acute arterial compromise,

**Figure 4 Where to assess the posterior and anterior tibial, dorsalis pedis and peroneal pulses**



**Table 1** Risk factors related to venous and arterial ulcers

Venous	Arterial
Bed rest for longer than four days	Angina
Deep vein thrombosis	Arterial surgery
Lower-leg fractures	Cerebral vascular accident, or stroke
Multiple pregnancies	Diabetes
Past surgery	Intermittent claudication
Past venous surgery	Ischaemic heart disease
Prior venous ulcerations	Myocardial infarction
Orthopaedic surgery	Peripheral vascular disease
Thrombophlebitis	Rheumatoid arthritis
Varicose veins	Smoking
	Transischaeamic attack

using Doppler and assessing limb colour, temperature, movement, pain, sensitivity and capillary refill, the ulcer itself must be assessed.

There are several clinical indicators that can help establish the aetiology of ulcers, including past medical history, risk factors (Table 1) and clinical signs and symptoms (Table 2).

If the aetiology indicates venous disease, the gold-standard treatment is compression bandaging, which may be impossible to initiate in the ED but must be applied only by competent practitioners, usually tissue viability or vascular specialists, to ensure it is safe and effective (Vowden and Vowden 2012).

As the number of ED attendances increases, wound-care specialists may need to consider training emergency nurses in this skill but, in the interim, ED nurses should refer patients with leg ulceration to vascular tissue viability specialists, or to their local community providers, before discharge.

Box 2 lists factors that should be included in the assessment of patients with leg ulceration who present at EDs (Dealey 2012).

Forms for recording details of a patient’s leg ulceration and the condition of the surrounding skin can be developed with specialist advice for different practice settings using the templates available at [journals.rcni.com/r/patientdataforms](http://journals.rcni.com/r/patientdataforms)

### Wound care

Substance abuse or time constraints should not alter the need for thorough wound review and dressing plans. In each case, it is important to describe accurately where the ulcer is located and its depth using descriptors such as ‘superficial’

**Table 2** Clinical signs and symptoms of venous and arterial aetiologies

Venous	Arterial
Related signs and symptoms	Related signs and symptoms
Aching or heaviness in legs	Atrophic, shiny skin on shin
Ankle flare	Blanching in feet or toes when they are raised above hip level
Atrophie blanche	Capillary refill time of less than three seconds
Induration, or hard woody feeling in skin	Cold foot
Itching over varices	Dusky skin colour on foot
Oedema	Gangrene on toes
Pigmentation, or brown staining	Loss of hair on leg
Ulcer in gaiter area	Loss of pedal pulses
Ulcer over malleolus	Muscle wasting in calf or thigh
Varicose eczema	Pain in lower legs or foot when raised
Varicose veins	Thickened toe nails
	Ulcers on toes

## Box 2 Factors to consider in assessment of a patient with leg ulceration

### Factors indicative of venous ulceration

- Family history of varicosities or ulceration
- Varicose veins: ask the patient to stand, and assess the length of his or her legs from groin to toes, both the anterior and posterior aspects
- Proven deep vein thrombosis (DVT) in affected leg
- Phlebitis in affected leg
- Pregnancy
- Suspected DVT
- Surgery, fractures or trauma to the leg: observe for scarring or signs of orthopaedic intervention such as knee replacements or ankle interventions
- Leg infection or cellulitis
- Observe for venous or brown, hemosiderin staining to the leg. This is permanent and can be a clear indicator of venous congestion, hypertension or ulceration

### Factors indicative of potential arterial or non-venous ulceration

- History of heart disease, stroke, transient ischaemic attack. Ask about dates and current medication
- Diabetes. Is the patient's diabetes controlled? What medication does he or she take?
- Ischemic rest pain. Is the pain worse at night? Does he or she sleep in a chair or hang his or her legs out of bed? What eases the pain?
- Smoker current or past. How long has the patient smoked and how many cigarettes a day?
- Hypertension. Does he or she take medication for this? If so, when?
- Bypass surgery. Observe for scarring
- Rheumatoid arthritis. Is the patient under specialist review for this and is he or she taking medication?
- Peripheral vascular disease or intermittent claudication

(Adapted from Dealey 2012)

### Additional questions to ask clients with a history of injecting into the lower limb to support vascular or ulcer assessment

It is important to emphasise that the information is needed to provide a clear history and produce a management plan

- How long has the patient been injecting and is he or she currently injecting?
- What substances are being injected currently or previously: heroin, cocaine, amphetamine, other?
- What is the main route of access? Ask the patient to show you and ask how many times a day he or she injects into this area
- Does the patient have any blood-borne viruses such as hepatitis C or HIV?
- What is the preferred method of injecting: intravenously, subcutaneously ('skin popping') or intramuscularly?
- If the patient is still injecting, has he or she experienced any pain, burning or paraesthesia?
- Is there a history of vascular injuries or conditions such as pseudo-aneurysm, abscesses or DVTs?
- Is the patient taking substitute medication such as methadone or buprenorphine?
- When and how did the ulcer occur? For example, did it happen spontaneously or was there any injury or trauma?
- Who normally dresses the ulcer and where is he or she based?
- What dressings has the patient used and found work well or badly?
- Does the patient have any topical allergies or sensitivities to creams, ointments, dressings or bandages?
- Does the patient have any pain with the ulcer and, if so, when is it worse and what relieves it?
- What is the patient's daily nutritional intake?
- Does the patient drink alcohol or smoke cigarettes? If so, what are the daily quantities?
- Ask for a urine sample and take routine observations including weight and height

or 'deep' depending on whether or not underlying structures such as tendon or bone are visible.

Visible tendon or bone is generally atypical of a venous leg ulcer so, if these structures are visible, a review by the vascular team is required.

The International Wound Advisory Board (Falanga 2004) offers a structured framework for the assessment and management of wounds, which is referred to as TIME, where T=tissue management (non-viable); I=control of infection or inflammation; M=moisture imbalance; E=edge of wound (which is not advancing). The pathophysiology of chronic wound healing is complex but in emergency care settings the main aims of chronic wound management, based on the TIME acronym, are summarised as follows (Ousey and Cook 2012):

- To provide continuity of care and, in keeping with professional standards and regulations, all wound-care observations, assessments and plans should be documented in patients' medical notes, avoiding jargon and written clearly, consistently and accurately.
- To maintain a moist wound environment and to control levels of exudate from the wound, to choose the correct dressing to promote and control moisture, and to maintain a balanced wound environment to promote healing and to help prevent the overburden of bacterial growth
- To ensure the edges of the wound and surrounding skin are protected from the exudate, perhaps through the sparing use of a barrier cream or film, to prevent maceration or excoriation.

■ To treat signs of local wound infection or bacterial burden topically with appropriate antimicrobial dressings. If there is a malodour from the ulcer, deodorising dressings should be considered as a secondary dressing if accessible. Most EDs have access to topical antimicrobials; if not, it is advisable to liaise with local tissue viability nurses to ensure such access.

Swabs should be taken from a chronic wound only if there is clinical evidence of infection: heat, redness, pain, malodour or a friable wound bed, for example. It is important not to mistake chronic inflammation for wound infection. Generally, if a patient is systemically well, the chronic leg ulcer is more likely than not to be infected locally and the bacterial burden topically manageable.

A bandage or retention dressing should be considered to secure dressings, protect the limb and help control oedema. It is advised not to stick adhesives to patients' skin because this can cause trauma and pain on removal.

A simple primary bandage secured with a crepe in a spiral technique from the base of the toes to two fingers below the knee can provide a comfortable and secure method of retaining dressings. After securing the dressing, a cotton liner can be used to cover the skin on the leg before bandaging, to retain the dressing but also to prevent irritation from the bandages.

It is also important where possible to wash the leg because patients with venous leg ulceration often have associated skin conditions and varicose eczema. If washing the leg, use warm tap water and, if possible, a lanolin and paraben-free emollient. Wash and moisturise the leg in a downward motion, not against the hair growth, to prevent folliculitis.

There are a number of additional harm-reducing techniques for managing wounds in patients who

use IV drugs (Pieper and Hopper 2005). For example, ED nurses can try to establish if patients are homeless; if so, they can direct them to homeless support teams or local support groups such as the charity, Crisis. Patients can also be given details of local harm-reduction programmes and programmes for needle and syringe exchange, and can be advised, with the support of medical or surgical teams, on how to inject more safely. ED nurses should also refer patients to primary care services such as walk-in centres, where they can have wounds dressed regularly.

## Conclusion

Delivering wound care in EDs, particularly for patients with ulcers of the lower limb, can be time consuming, and IV drug users living with this condition can present with specific challenges for ED nurses. Central to all good health care are effective therapeutic relationships between clinicians and patients, which for some IV drug users start in EDs (Nuttall 2009).

The assessments and clinical guidance described in this article should help ED nurses care for patients with leg ulceration as a result of injecting into the lower limbs.

Engaging with patients in their wound care can promote commitment to treatment regimes and in turn concordance, which helps patients to access more appropriate services for chronic wound management.

## Find out more

Forms for recording information about patients with leg ulcers are available at [journals.rcni.com/r/patientdataforms](http://journals.rcni.com/r/patientdataforms)

## Online archive

For related information, visit our online archive and search using the keywords

**Conflict of interest**  
None declared

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# Leg ulceration in intravenous drug users

## How to use this assessment

This self-assessment questionnaire will help you to test your knowledge. It comprises ten multiple choice questions that are broadly linked to the feature starting on page 16. There is one correct answer to each question. You can test your subject knowledge by attempting the questions before reading the article, and then go back over them to see if you would answer any differently, or you might like to read the article before trying the questions. The answers will be published in the next issue of Emergency Nurse. When you have completed your self-assessment, cut out this page and add it to your professional portfolio. You can record the amount of time it has taken you to complete and add comments in the space provided.



**1. Which of the following is a common sequela for intravenous (IV) drug users who regularly inject into the lower extremities?**

- a) Chronic venous hypertension
- b) Wound infection
- c) Pseudo-aneurysms in the groin
- d) All of these

**2. Which of the following is rarely a reason why IV drug users attend EDs:**

- a) Pain
- b) Inability to access local homeless teams
- c) Refusal to use the ED appropriately
- d) Inability to access specialist centres for dressing changes

**3. In someone with chronic leg ulceration, which of the following constitutes a developing emergency?**

- a) Deep vein thrombosis (DVT)
- b) Abscess formation
- c) Limb ischaemia
- d) All of the above

**4. Leg ulceration is defined as a loss of skin below the knee that takes more than:**

- a) Four weeks to heal
- b) Six weeks to heal
- c) Eight weeks to heal
- d) 12 weeks to heal

**5. Which of these is not a classification of leg ulcer?**

- a) Arterial ulcer
- b) Rheumatoid ulcer
- c) Topical ulcer
- d) Malignant ulcer

**6. According to the article, what percentage of patients with leg ulcer have had DVT?**

- a) 20
- b) 35
- c) 50
- d) 75

**7. The remainder of ulcers result mostly from:**

- a) Abscess formation
- b) Incompetent valves in the veins
- c) Both of these
- d) Neither of these

**8. The formula for calculating ankle brachial pressure index is:**

- a) Ankle systolic pressure divided by brachial systolic pressure
- b) Ankle systolic pressure minus brachial systolic pressure
- c) Ankle systolic pressure multiplied by brachial systolic pressure
- d) Brachial systolic pressure minus ankle systolic pressure

**9. To determine whether an ulcer is venous or arterial, it is best to:**

- a) Perform a Doppler
- b) Make a judgement based on clinical examination
- c) Make a judgement based on X-ray with contrast media
- d) Undertake a computed tomography scan

**10. In the UK, compression bandaging aims to improve venous return in the foot and calf by maintaining the ankle at what pressure?**

- a) 20mmHg
- b) 40mmHg
- c) 50mmHg
- d) 60mmHg

This self-assessment questionnaire was compiled by Lorna McNulty, senior lecturer in emergency and unscheduled care at the University of Central Lancashire

This activity has taken me \_\_\_\_\_ minutes/hours to complete. Now that I have read this article and completed this assessment, I think my knowledge is:

Excellent  Good  Satisfactory  Unsatisfactory  Poor

As a result of this I intend to: \_\_\_\_\_

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**Answers to self-assessment questionnaire number 68**

1. c, 2. c, 3. a, 4. d, 5. b, 6. d, 7. d, 8. c, 9. d, 10. b

# Tissue viability services for intravenous drug users

The life and mission of Florence Nightingale is legendary all over the world; a pioneer of nursing, her dedication to the wounded soldiers during the Crimean War remains an inspiration. Even with challenges that nurses face today, Nightingale remains a steadfast example of the fundamental moral obligations and basic nursing practices within healthcare: to care for the sick, wounded and vulnerable. My intrigue with Florence Nightingale began when I read one of her many quotations, this one taken from personal correspondence (Cook, 1913):

**‘So never lose an opportunity of urging a practical beginning, however small, for it is wonderful how often in such matters the mustard seed germinates and roots itself.’**

This, for me, summed up everything that is wonderful about nursing care—the simple therapeutic touch, a kind word, a smile and the privilege of being able to nurse the sick, wounded and dying and their families at a time often faced with uncertainty and vulnerability. Even after nursing for 15 years, I never tire of the admiration and respect I have for my colleagues across the world who continue to provide nursing care to those in need.

The Florence Nightingale Travel Scholarship is funded for scholars to undertake study on an aspect of practice or education in the UK or overseas. My scholarship journey began in 2012 and my aim was to explore and compare leg ulcer/wound care and tissue viability services for intravenous drug users in primary care in England, concentrating on Northern England and London.

My first encounter with patients with leg ulceration who had a history of injecting illicit substances began in Aberdeen, where I worked in the vascular unit at the Royal Infirmary. This particular population made me very curious about their lifestyle, body image and their conceptions of health and illness. Often they presented clinically very unwell with ruptured pseudoaneurysms or infections from abscesses or leg ulcers. Socially, there was usually a story behind their drug use and fall into addiction; however, through it all they remained resilient, independent and full of character! I was intrigued and wanted to work more closely with this client group. Pain, quality of life and concordance remain real issues for practitioners managing leg ulceration within this group.

Findings from the 2014/15 *Crime Survey for England and Wales* (Home Office, 2015) show that around one third (34.7%) of adults aged 16 to 59 said they had taken an illicit drug in their lifetime (around 11.3 million people). This is similar to recent years but an increase from 30.4% in the 1996 survey. This is likely to be an effect of the ageing population, as last-year drug use has fallen compared with 1996. A total of 15.5% of adults aged 16 to 59 (5.1 million) had taken a Class A drug in their lifetime, a statistically significant increase from 9.6% in the 1996 survey. According to the survey, 2.2% of all adults aged 16 to 59 were classed as frequent drug users (Home Office, 2015).

The main purpose behind the scholarship visits was to understand the different services provided for intravenous drug users living with leg ulceration. By discussing and sharing best practice, challenges and successes of managing this client group, there was the potential to develop a greater understanding and clinical skill in managing leg ulceration and wound care.

During my travels I met some inspirational nurses who go above and beyond the call of duty to care for their patients. I was also able to come closer to the culture and complexity of clients living with leg ulceration who were still using illicit substances either by injecting or another means, or clients in the process of rehabilitation or coming to terms with their addiction physically and emotionally.

One of the things that stuck me from the outset was that substance misuse has no limits and can affect individuals at any time in life from all corners of society, regardless of age, sex, race or religion. The effect of substance misuse on individuals and their families can be devastating, not only from a medical and psychological perspective in terms of treatment and recovery; it also impacts on crime and homelessness. The social detriments and cost of injecting can include financial difficulties, unemployment, homelessness, criminal prosecution and the breakdown of the family network, as well as mental health problems (Reid and Klee, 1999; Craig and Hodson, 2000; Neale, 2001; Hammersley et al, 2007).

Managing leg ulceration within this group presented many practical challenges for clients such as travelling to and turning up for an appointment; often they could simply not afford the bus or train fare and would walk for up to an hour if they could to get to the clinics. Timing

and reminders for appointments were also essential as clients were often not suited to an early appointment and could forget. Simple tasks like sending a free text message or calling before their appointment worked wonders and meant that consistency could be built up with dressing changes. The majority of clients I met welcomed the opportunity to share their story. Living with leg ulceration can be a debilitating and life changing condition; however, clients presented with admirable resilience and positivity.

Three years later I can say that my scholarship was much more than learning about wound management with this client group, although it was helpful to share ideas with other health professionals and clients. Many of us keep in touch and I still visit the London clinic monthly to meet with clinicians and clients.

The real value of the scholarship was the reflection on my own nursing practice. Patients can teach us so much about ourselves as nurses and we can continuously learn from their experiences, struggles, stories and courage.

I will finish with a passage from my original application for my scholarship journey in 2012: ‘It could be argued that nurses should not be so emotionally involved and should acquire a stiff upper lip in the encounters they have throughout their profession. However, I would argue that nursing represents to me the cornerstone of care, compassion, kindness and empathy, so are we not free to show these as we see fit to those who are most in need of it?’

**BJN**

*With thanks to the Florence Nightingale Foundation, Professor Elizabeth Robb, Sandra Charitable Trust and Dr Alison Crombie for believing in my vision around exploring leg ulcer services for intravenous drug users and for providing me with this unique opportunity to visit these areas around England.*

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# Drug policy, intravenous drug use, and heroin addiction in the UK

Jemell Geraghty

## Abstract

**In order to fully understand and appreciate today's drug problem in the UK, the foundations of drug legislation and the history of drug evolution require exploration. This paper critically examines the history of drug policy and the growth of heroin addiction from the perspective of a novice researcher who works closely with intravenous drug users in relation to leg ulceration and wound care in the acute setting. Today's drug policy has come a long way in understanding the problems of heroin addiction and establishing services to meet intravenous drug users' needs and the needs of society. This paper highlights the early warning signs of drug addiction and growth within the UK from an early stage with key areas such as who the early users were and how addiction grew so rapidly between 1920 and 1960. Current policy and decision makers as well as clinicians and researchers in this field must understand the impacts of past policy and embed it within their decisions surrounding drug policy today.**

**Key words:** Intravenous drug user (IVDU) ■ Heroin addiction ■ UK drug policy ■ Researcher ■ Service provision

**H**ow can the history of drug policy prove relevant in today's healthcare practice? How does the past impact on service provision and the way health professionals consider current drug policy as well as today's intravenous drug users (IVDUs)? The main focus of this paper is on IVDUs and the growth of heroin addiction in the UK. This paper aims to empower health professionals in the care they provide to patients by enhancing their knowledge of historical policy and highlighting its value in understanding how current drug policy came to be.

Cherubin and Sapira (1993) explain that the term 'intravenous drug user' (IVDU) is now preferred to the previous broad term of 'drug user', as it focuses on the main medical complications of 'injecting' within this population. There are various challenging conditions associated with injecting including, hepatitis and bacterial infections, abscesses, HIV/AIDS, vascular injuries, endocarditis, arthritis and other rheumatologic complaints (Stein, 1990). In

addition, social consequences of injecting surrounding this group can include financial difficulties, unemployment, homelessness, criminal prosecution and the breakdown of the family network as well as comorbid mental health problems (Reid and Klee, 1999; Craig and Hodson, 2000; Neale, 2001; Hammersley and Pearl, 2007). Gosden (1987) emphasizes that there is no psychological or physical profile of a typical drug user; addiction can affect anyone, whether rich or poor, young or old and all drugs that cause a user to become an addict, other than those given with medical supervision, are hazardous to the user and society.

The management of IVDUs is costly to the economy and society on both a local and national level. The National Audit Office (NAO) (2010), estimated there to be one third of a million problem drug users in England and highlighted the progress into tackling drug use. The Government spent an estimated £1.2 billion in 2009-10 with the overall objective of bringing down the £15 billion-a-year cost to society of problem drug use (NAO, 2010), the results of which are still unclear. The home office 10-year drug strategy (2008-2018) aims to restrict the supply of illegal drugs by reducing the demand for them. It focuses on protecting families and strengthening communities by tackling drug-related crime and anti-social behaviour, as well as preventing harm to families affected by drug use, especially children and young people. The overall aim is to provide new methods of drug treatment involving communities and social reintegration (Home Office, 2008). The European Monitoring Centre for Drugs and Drug Addiction (EMCDDA) (2005) highlights that social reintegration involves integrating former or current drug users into the community, using the three pillars of housing, education and employment.

As well as the above cost to society, there is a direct cost to the NHS in medical attention provided to this group. Hope et al (2008) estimated that over 30 000 IVDUs seek health care for injection site infections in England each year with at least 18 500 of them requiring hospital admission. The study highlights that these infections are preventable and estimates the cost of injection site infections to the health service in England to be at least £15.5-19.2 million per annum. Lord Darzi's report (Department of Health (DH), 2008) envisaged *High Quality Care for All*, with a stronger, proactive focus on public health and helping people stay healthy by tackling substance misuse and preventing long-term conditions. Although alcohol and smoking were addressed alongside obesity as part of the focus on public health, it failed to highlight the issue of drug addiction. This issue of drug addiction being overlooked in policy making

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features throughout this paper and demonstrates the impact it is likely to have had on the UK's drug problem today. The Government Equalities Office (2010) published a report on building a society where the rights, equality and opportunity for individuals are at the core of British society. Although this is commendable in relation to the drug user population, it may be difficult for society to facilitate the reintegration of drug users, both current and past, back into society. This paper will demonstrate how the stigma attached to drug use has developed within society over time.

Berridge (1999) explores how the most influential part of any policy is 'past policy' and how today's drug policy is built upon yesterday's theories of drug control and regulation. Blank (2002) adds that there are further influences that create policy, including the media, pressure groups, individuals, politicians and the government: these groups all play an important role in the development of policy. Allsop (1995) explains that health policy has been limited primarily to government targets about action, which relate to the maintenance of good health in individuals and populations as well as the treatment of the sick and care of the frail. Although Allsop (1995) recognizes that other organizations in society contribute in statements towards health, the hypothesis is that the government has ultimate power and therefore, ultimate control and authority to act. Cawson (1982) argues that health policy is developed by the government and the medical profession and is a result of negotiation and compromise in avoidance of public enquiry. This obvious struggle between the medical profession and the state is particularly relevant to past drug policy and will be discussed later in the paper.

Today's drug policy in Britain is embedded in previous efforts of the state to control drug use. This form of policy is known as 'incremental policy'. It refers to policy that has already been implemented and is then refined and improved as mistakes are removed or adjusted. The theory of incremental policy is evident within the evolution of drug policy in the UK, however, this was not always necessarily an advantage. As monumental changes, such as growth of the black market and societies' acceptance of recreational drug usage, were taking place between the 1920s and 1950s, policy failed to keep up. Instead, past policies were refined under the belief this would be adequate, along with the argument that moral obligation and social order would prevent drug addiction from spiralling out of control. Unfortunately however, incremental policies were not sufficient to withstand the growth of heroin addiction and IVDUs, nor could the moral obligation of society withstand the speed in which heroin addiction grew within this time frame.

### Search strategy

In order to investigate the literature surrounding the history of the UK's drug policy from a social, economic and political perspective that impacts on the provision of health care, a basic search strategy framework was used. The databases explored were PubMed, Cochrane, CINAHL plus and Scopus. These core resources, as well as websites such as Google Scholar and Infomine, were used to ensure the literature search covered a significant proportion of the available published and

unpublished literature, while identifying the most up-to-date and ongoing research. Detailed searches were undertaken within specific search limits, these limits included studies involving humans, conducted in the English language and within the date range from 1920 to 2010. Key terms and the authors of many recognized articles were used for each individual search. Some of the search terms included were drug, policy, intravenous user, service, cost, social, political and economic. The authors searched were established names in drug policy literature such as Berridge, Bewley, Strang and Gossop. The British Library provided a substantial amount of the literature for the early time frame, as this was not accessible online. The reference lists of selected literature were also explored in detail to broaden the search and the snowball sampling approach (Polit et al, 2001) was often used by manually searching for references to ensure a thorough search of the literature.

In order to appreciate how current drug policy in the UK has developed and assimilate the substantial literature surrounding this ethos, it is first necessary to understand the origins of policy and critically analyse the history that made drug policy what it is today.

### The early years of drug policy

The first legislative measure attempting to establish the regulation of narcotics as a matter of social policy resulted from conditions of the First World War. The first Dangerous Drugs Act, passed in 1920, is widely regarded as the foundation of British narcotics legislation in which the manufacture, sale, possession and distribution of morphine, cocaine and heroin were rigorously regulated (Berridge, 1978). Berridge (1984) adds that the impact of war altered the focus of narcotics and subsequently, the perceived needs of the war effort allowed the movement of stricter narcotics regulation and brought government into a position of authority. Malcolm Delevingne, who worked in the home office and was also a member of the Leagues Opium Advisory Committee, was determined to keep the Dangerous Drugs Bill within home office control although the medical and pharmaceutical professions were contenders, each with a dominant source of power. Berridge (1984) emphasizes that doctors were able to influence the creation and path of legislation by means of the parliamentary committee of the British Medical Association as well as in the House of Commons itself through the members of parliament who were also doctors.

The secondary legislation contained in the Dangerous Drugs Regulations of 1921 (DH, 2005) laid down the formal obligations of doctors and pharmacists with regard to prescribing and dispensing of dangerous drugs in written form, which still exists today. It is of interest to note that a regulation, proposed in 1922, that doctors should not be permitted to prescribe a controlled drug for personal use was withdrawn by the home office following objections from the British Medical Association. In addition, a further proposal by the home office in 1923 to restrict the entitlement of medical practitioners to possess, prescribe or administer dangerous drugs to non-practicing or retired medical fellows was also abandoned (DH, 2005).

The home office became increasingly concerned about the therapeutic practice of opiate prescribing by doctors and whether treatment for addiction could be regarded as legitimate medical practice. The medical profession interpreted this concern as official intrusion into the sanctity of the doctor/patient relationship. As a result by 1924 the home office had approached the Ministry of Health, querying the propriety of the prescribing practice doctors (Spear, 1994).

Following this approach in September 1924, a departmental committee was appointed under the chairmanship of Sir Humphry Rolleston to report on the problem. The Rolleston Committee, which held a total of 23 meetings, was entirely medical in constitution and took the oral evidence of 35 witnesses, of whom 24 were medical men. The absence of women within the committee and among the medical profession showed the power of male dominance within society at this time and the struggle for professional women. Lutzker (1969) points out that for most of the 19th Century, women in Britain were excluded from medicine, explicitly or implicitly, by every possible means that could be contrived by the medical profession, universities and even the government. However by 1911, there were almost 500 female doctors in England. Yet, still none were represented within this committee. Simonton (1998) adds that the tradition of male professions restricted not only women's entry into medicine, it also controlled their movement once there. The remaining members of the committee consisted of four witnesses from the British Medical Association, three from the Pharmaceutical Society and those on behalf of the wholesale and retail pharmacists, again showing the control held by the drugs and trade industry at this time (Harding, 1988).

Interestingly, the Departmental Committee's Report (1926) highlighted a deeper question within the agenda for controlling morphine and heroin in the cases of doctors who were also addicts. However, the report fails to mention how this was approached or managed. The report also highlighted how exceptionally large quantities of morphine and heroin were being prescribed by particular practitioners. There is a question surrounding the validation of prescribing and whether such actions broke the law. The report, however, failed to be explicit in determining whether medical practitioners were corrupting professional accountability. The report added that the problem of addiction to morphine or heroin within the country was rare and had diminished in recent years. It emphasized that the moral prevention and control of addiction was in the hands of the medical profession, as it was through them alone that the drug could be acquired.

The report mentions the sociological aspects surrounding these drugs which required closer study, although it failed to recognize in its conclusions and recommendations how this should have been investigated further. In retrospect, it is unfortunate that the committee did not recommend further investigation into the sociological aspects surrounding morphine use at that time. This may have prevented the impact in later years of drug usage on mental health, such as depression, isolation and suicide, and the subsequent impact on families, children and the community affecting everything

from finance and employment to housing. Stimson and Lart (1994) add that the medical approach to drug problems resulted from an adjustment between the state and the medical profession. In the struggle between the state's desire to tackle the drug problem and the medical profession's will to retain power, clinical freedom emerged untouched.

### **Changes within narcotic addiction**

For the next 40 years, changes within drug policy were deemed unnecessary and the general thought prior to the 1960s was that there were only two types of drug dependence in Britain; these came in the form of alcohol and tobacco. Still, there was little attention to alcohol or tobacco consumption and no understanding of the damages of addiction caused by these everyday substances. Up to this time, the drug problem within the UK had been absent from the public eye and a similar picture was present across Europe with no substantial drug problem acknowledged to be able to test the sufficiency and appropriateness of both policy and service provision (Connell and Strang, 2005). However, Bewley (1965a) highlights a change in the pattern of narcotic addiction in the UK. Before 1954, most addicts were a result of accidental addiction in the course of therapy or were professionals such as doctors, nurses and pharmacists who had become addicted following their ease of access to narcotics. Bewley (1965a) undertook a survey of heroin addicts known to the home office between 1954 and 1964; heroin was specifically monitored as most of the newly recorded addicts were taking it. The results showed that 57 heroin addicts were known in 1954 and 450 new cases were added within the following 10 years. Most of these cases since 1955 were British and this number was increasing at an accelerated rate. It was estimated that between 200 and 300 new British heroin addicts would be recorded in 1965. The majority had become addicted from a non-therapeutic source although the paper fails to give examples of this. Those who became addicted in the course of treatment were aged over 60 and those addicted through a non-therapeutic source had a mean age of 24 years. The paper only separates Canadians from the British and then classifies the remaining as 'other nationalities', with most members of the latter group being addicted for many years prior to their entry to the UK. The paper also highlights that the mean age at the time of death of addicts who had become addicted to heroin from non-medical sources was 34 years. It concludes by characterizing three groups of heroin addicts in the UK. The first is a small number of addicts who had developed the addiction in the course of treatment, the second, a large number of young British addicts whose numbers were rapidly increasing and who acquired addiction through a non-therapeutic source, and finally, a group of older addicts who came to the UK with a mean age of 10 years higher than that of the British addicts, most addicted for many years from a non-therapeutic source. Bewley recognizes, even at this stage, that there was a black market where addicts had more narcotics prescribed than were actually needed and which were then sold on to others. This highlights that addiction of this type which had epidemic case-to-case spread was a major public health concern. Bewley (1965b)

adds that the epidemiological research into drug addiction at this time was practically non-existent and that treatments for addicts were inadequate. Mental hospitals were overcrowded and understaffed and as a result, hospitals were unable to provide sufficient follow up or identification of individuals with mental illness. Bewley criticized the Interdepartmental Committee for failing to review and update policy in relation to drug addiction and stressed the need for a regulatory body that would continuously review the situation.

### Evolution of drug policy from 1960

The Ministry of Health and Department of Health for Scotland (1961) appointed an Interdepartmental Committee for drug addiction who published the First Brain Report. The report still failed to recognize that there was a growing problem of opiate addiction in the UK and called the incidence of addiction to dangerous drugs 'small'. The report ignored figures provided by the Home Office which showed an increasing number of addicts and suggested that there was no cause to worry about any increase in the addict population. Addiction was regarded as an expression of mental disorder rather than a manner of criminal behaviour. It is apparent that the committee was ill-informed about the concept of addiction and its origins, as well as users' habits and motives. There was no recommendation for the provision of institutions to treat drug addiction and the best unit for the initial treatment of the established addict was the psychiatric ward of a general hospital. Although recommendations were made for long-term supervision and rehabilitation once the addict recovered to prevent relapse, such as social services and GP input, it failed to explore these vital preventative strategies, making up the foundation of future setbacks. The report acknowledges that prevention is preferred to cure but places this responsibility and duty on the public by highlighting that healthy attitudes of the public would overcome this problem and keep the incidence of drug addiction to small numbers. However, again it dismisses the numbers as being few and refers to the problem as special. Finally, the committee recommended that a system of registering addicts was not needed or desired. In the end the report failed to acknowledge a problem that would undoubtedly escalate. Its lack of vision around the population of drug users and the future impact of this on society could be considered today as reckless.

The 1960s were a time of significant social upheaval and change, particularly within London's West end youth culture, which witnessed experimentation with new ways of seeking pleasure, often through taking drugs (MacGregor, 1989). The Brain Committee reconvened in 1964 and produced its second influential report, *Drug Addiction* (1965). This report presented comprehensive recommendations amending the understanding around the UK drug problem which had remained largely unchallenged and unaltered since the Rolleston Report in 1926 (Connell and Strang, 2005). One of the most significant developments within the report was the definition of an addict which was regarded in the First Brain Report as an expression of mental disorder. The definition had evolved in defining an addict as 'a person who, as a result of repeated administration,

has become dependent upon a drug controlled under the Dangerous Drug Act and has an overpowering desire for its continuance, but who does not require it for the relief of organic disease' (Ministry of Health and Scottish Home and Health Department, 1965). This definition shows a growing understanding of the habitual nature surrounding drug dependency. Other recommendations included the compulsory notification and up-to-date list of addicts managed by the Home Office, the establishment of specialist centres with back-up inpatient treatment and research into addiction, especially in the London area. The report acknowledged that addiction in the rest of the UK did not seem to be a serious problem, however, recommended that health departments should ensure that all regional hospital boards make suitable arrangements for the treatments of addicts in selected hospitals according to locality. The introduction of limits in prescribing heroin or cocaine for doctors was introduced to ensure tighter regulations around narcotic administration. Finally the report recognizes that drug dependency was a changing problem which required constant observation in the form of a standing advisory committee which would monitor and report any developments. Overall the report was a success in that it finally accepted the challenges surrounding drug addiction, treatment, prescribing, monitoring and research.

### Growing numbers of heroin addicts

Hewetson and Ollendorff (1964), two GPs in London, realized that the numbers of heroin and cocaine addicts that were attending for consultation (three or four over the last two and a half years) was not a true representation of the user population. There were large numbers of users who were unable to get a prescription privately and were anxious about consulting the GP about their addiction; therefore, they obtained the drugs on the black market. After interviewing users, it became apparent that in spite of the British medical tradition's liberalism, the services provided for users was insufficient. The authors then proposed to accept any genuine user who was either unable to get a prescription on the NHS or who could not afford a private prescription. Within a year, the list of users rose to 100 and the paper presents some significant results surrounding the sociological factors of drug addiction. The study highlighted addicts as a group of unstable patients who needed further input in relation to psychiatric diagnosis and that there needed to be more research into the mental, physical and social breakdown of this group. The paper also emphasizes that GPs were unable to cope with treating this growing population alone and that neither general hospitals nor mental hospitals were equipped for treating or dealing with the withdrawal of addiction. The paper highlights the close-knit society among drug users and the mutual support that exists within it. Drug users whose history was studied in greater detail revealed deprivation and prolonged lack of love in childhood which certainly played a role in the participants' addiction. The paper admits that the most tragic of all results was the surrounding social disintegration with drug users resorting to desperate means to obtain their next fix and a general disregard for family, work, social cleanliness

and dress. Finally, the authors acknowledge that work with and for drug users required inexhaustible patience and was in its early stages. In order to gain knowledge around all aspects of drug addiction and care, further research was needed.

Bewley and Ben-Arie's (1968) initial study of 100 heroin inpatients highlighted the need for legislation in the UK to detain drug users as inpatients in hospital to overcome addiction. The paper highlights that Britain was the only country at the time where heroin was prescribed for drug users and that none of the participants were followed up on discharge by the prescribers who were mainly GPs; to establish the effects of heroin on health, work abilities or social adjustment.

Bewley et al (1968) further investigated the morbidity and mortality from heroin dependence using a survey of drug users known to the Home Office. Unfortunately, this in itself limits the numbers of the study, however, the paper still presents some important information. It identified 1272 heroin users including all cases first known to the home office from 1947 to the end of 1966. Of these, 890 had taken opiates in 1966 and 89 had died. The causes of death included nine from suicide, seven from overdose, six from violent deaths, four sudden deaths (probably the result of self-administered narcotics), apparently 16 'accidental overdose' and 15 deaths were directly caused by sepsis. Of the remaining 12 'natural deaths', almost all were directly or indirectly related to drug usage. There were 293 not known to be taking opiates and 189 had been in prison, hospital or a related institution. The rate of new heroin users was doubling every 16 months. The mortality rate among non-therapeutic users was 28 times the expected rate, and of new cases since 1966 - 40% were under the age of 20. This paper is significant as it shows the growing numbers of drug users and also introduces the factors of institutions and crime in drug usage and drug-related deaths. It also recognizes changes in the age of new users, with 40% under the age of 20; this population would undergo the long-term physical, psychological and social effects of drug usage throughout their lives, whether they continued to use or not. The paper also provides depth into the impact on users' mental health which resulted in suicide and overdoses. Overall the paper gives a good insight into the extent of the drug problem developing in the UK.

Spear (1969) presented a historical paper on two major drug trafficking instances that occurred in the 1950s in London, particularly in the West end, which had a significant effect of the growth of heroin addiction. This paper is the first example of large scale trafficking which involved selling drugs to non-drug users. Prior to this, the user population was thought to have been content to retain the drugs within groups. The paper examines the activities of a particular user, Mark, and it is significant as it demonstrates the complex connections and relationships drug users had in terms of their addiction and the black market.

By the end of 1968, there were just over 1 000 drug users notified to the Home Office and by 1989, this had multiplied to nearly 15000, a growth largely accounted for by the heroin epidemic of the mid-1980s.

## The clinic system

Following recommendations of the second Brain report (1965), the Government decided to establish a network of new drug user treatment clinics in each of the major teaching hospitals in London. The establishment of the NHS would ensure treatment was available free at the time of need. The new clinic system was ready to take responsibility from GPs and hospital doctors and was established according to plans prepared by the Ministry of Health (1967). The Strang and Sheridan (2006) paper looked at the records from a London drug clinic over the first 15 years of operation (1968-1983) and concluded that the initial setting up of clinics was largely to take responsibility for the prescription of drugs, particularly heroin. However, by the mid-1980s, the focus had moved towards the prescribing of methadone. The data presented in the paper shows that this change in prescribing was gradual. Interestingly, the paper found that injectable prescriptions of heroin continued to comprise more than half of the prescriptions issued by the clinic for nearly the entire 15-year period studied. The paper revealed that it was not until 1982 that injectable prescriptions fell to less than half of the prescriptions issued by the clinic. The paper highlights that the decade of difference between the figures was a result of the significant increase in the injectable methadone that was prescribed from the early 1970s onwards. Bean (1974) added that with the introduction of the clinics came a change in the numbers of heroin users. With treatment centres reducing overprescribing, drug users were forced to attend the centres for further supplies. Thereby, the Home Office was notified, meaning the number of users were being more accurately monitored. However, in contrast this could have meant an increase in the black market as addicts tried to obtain more drugs than were being prescribed.

## Conclusion

Today there has been a significant amount of work focusing on issues of prevention, treatment and protecting families relating to or involved with drug use. The National Treatment Agency for Substance Misuse (NTA) Health Authority within the NHS was established by the Government in 2001 to improve the availability, capacity and effectiveness of treatment for drug misuse in England. The NTA works in partnership with the Department of Health, the Home Office, the Ministry of Justice, the Department of Children, Schools and Families, the Department for Work and Pensions, the Department of Communities and local government. This initiative aimed to reduce the harm caused by drug misuse to individuals' wellbeing and to communities' public health through appropriate treatment. The overall goal of the NTA was to double the number of people with well-managed drug treatments between 1998-2008 and support addicts recovering from drug dependency in hopes of reintegration back into society. The NTA prioritizes support for families and the rebuilding of lives, building on research underpinning drug treatment and benefiting communities through better health and stable families (NTA, 2010a). The information provided by this agency for the public covers areas such as incidence and prevalence of drug use, information for young people who may be presented with drug issues and information on drug services and treatments. It caters for all

including health professionals who treat drug users, service users, families and carers and the general public.

The most significant change within drug services and policy development today is that there are clear plans to challenge the drug problem within the UK with positive goals and the implementation of strategies. One of the most notable documents is the NTA (2009) *Story of Drug Treatment*, which is a journey of success in tackling drug dependency within the UK. Finally, the NTA (2010b) when asked: 'What does a typical dependent drug user look like?' The answer is somewhat different from that of previous years. 'There is no such thing as a typical drug user. People with drug problems come from all walks of life and different backgrounds'. It appears that drug policy and service provision has come a long way since the first legislations of the 1920s and this paper has provided a review of its evolution between 1920-1960. The evidence of past policy and the drug users of that time should be forever embedded in the minds of current policy and decision makers. As clinicians we should keep in mind that today's drug use simply did not just come about in last decade. There is a complex history that led to where we are today in terms of policy, service provision and indeed, drug users themselves. We can bring the lessons of past policy to the forefront of care by using them to improve our understanding around drug abuse and its population. **BJN**

*Conflict of interest: none*

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### KEY points

- There is an important history to remember and reflect upon when considering the development and growth of heroin usage and addiction in the UK
- Understanding and researching the history of drug policy and growth of heroin addiction is significant in understanding the complex origins of patients' addictions and should help in the development of services
- The evolution of past policy must be embraced by clinicians who work with intravenous drug users or drug services
- Policy must continually evolve and improve to ensure services meet patients' needs, move with the times, and ensure drug problems are challenged



## IN BRIEF



## KEY WORDS:

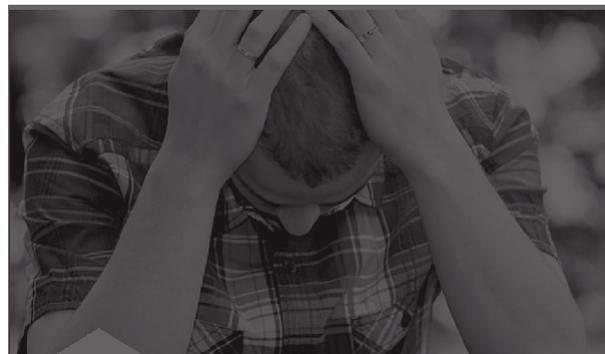
-  Complex wounds
-  Pain
-  Holistic assessment
-  Reflection

# Managing pain in wound care

Jemell Geraghty

**P**ain management in wound care is a daily challenge for nurses and in a much wider context is a psychosocial phenomenon, uniquely complex to each individual person who experiences it. It is part of a nurse's professional duty of care to alleviate wound pain. Pain is a multifaceted experience, for which there is no 'one-size-fits-all' management approach in relation to wound care; rather, it is vital to emphasise the importance of assessing each person as an individual (Gloth, 2011).

Credit: Sander van der Wel@wikicommons.com



*Wound pain can have a devastating effect*

**Figure 1.**  
*on patients' lives.*

Nurses should approach the management of wound pain in an objective and holistic manner, listening to the individual's experience of pain and how it impacts on their life. They should also listen to the patient's experience of different treatment options that have been used to alleviate pain, and what may or may not have worked in the past.

Due to the business of clinical life and growing caseloads of patients both in numbers and complexity, pain has the potential to be misinterpreted which, in turn, can lead to it being mismanaged.

This can have a detrimental effect on a person's daily life, relationships, job and confidence. This article will explore a number of everyday approaches to assessing pain, as well as providing practical tips and strategies aimed at relieving pain in wound management.

## PAIN PERCEPTION

The author asks the question that with the business of clinical life, do we as nurses sometimes become

blasé to the complex assessment and management of pain?

Young (2007) highlighted the many myths surrounding wound pain, such as the idea that older people have greater tolerance, or that certain wounds are more painful than others, e.g. the deeper the wound, the more painful it is.

The assessment and management of pain does not sit within a tidy box of structure and alignment. Thus, it is important that nurses allow themselves the time to assess pain, as this can influence the patient experience at that point of contact and in the future. Assessing

### Top tip:

#### Time management in wound

care is a skill in itself in terms of communicating with the patient, cleansing and redressing wounds, as well as tidying up and ensuring that all documentation is accurate and up to date. Keep a diary to reflect on how you manage your time and consider if and how this could be improved.

*Jemell Geraghty, lead nurse, tissue viability, Royal Free London NHS Foundation Trust*



THE SCIENCE — ASSESSING WOUND PAIN



The assessment of wound-related pain should be an ongoing process, involving negotiation and partnership between nurse and patient. It is important that nurses note the effects of analgesia and dressings on pain levels, as well as any subtle changes in discomfort (Day, 2013). The underlying aetiology of the pain must be identified if treatment is to be successful. It is worth noting that there may be a number of contributing factors influencing wound pain, such as soft tissue inflammation, infection, underlying peripheral arterial disease, and musculoskeletal or neurological disorders. Various diagnostic tools such as Doppler assessment, Duplex scanning, X-ray, magnetic resonance imaging (MRI) or tissue biopsy alongside microbiology may be required to identify the underlying cause of pain.

Credit: Squeezehoy@flickr.com

wound pain cannot be overlooked regardless of caseload pressures and demands on resources, as side-stepping this fundamental aspect of patient treatment potentially removes the care from practice. Nurses understand that there is often no cure for wound pain; however, by offering therapeutic techniques and reassurance, the patient's pain experience can be alleviated or improved.

REFLECTION

One of the first practical steps in managing a patient's pain is being self-aware and reflecting on practice. This requires nurses to 'take a step back' and ask some searching questions about the way in which they are managing a particular patient (Table 1). In the author's clinical opinion, the concept of pain management has as much to do with exploring the nurse's views, judgements and

practices of managing pain, as the phenomenon of pain itself.

Essentially, pain means different things to different people and is often dependent on a number of external and internal factors. It is a biopsychosocial phenomenon, which means that the patient's pain experience, and the assessment of pain itself, are influenced by biological, physical, social, emotional, behavioural, spiritual and cultural factors (Richardson, 2012).

Roberts' (2013) guide to holistic nursing brings together an abundance of literature to support nurses in psychotherapeutic approaches to care. He views nursing as a therapeutic activity and, by adapting psychotherapeutic techniques, describes how nurses can set the foundations for best practice when managing wound-related pain (Table 2 illustrates some of the recommended activities).

Table 1: Reflective questions that nurses can ask themselves

Question
> What does managing pain mean to me in practice?
> What are my own thoughts about pain management?
> Does my own experience of pain, or managing pain in others, affect how I assess patients' pain?
> Do I regularly keep up to date with current evidence in the management of pain in wound care, or
> there anything I could do to improve my current knowledge?
> Do I really listen and observe my patients when they are speaking about pain, or appear to be in p
> or discomfort?

ASSESSMENT

Any assessment of wound-related pain (see 'Science' box above) should include a thorough evaluation of:

- > The pain's origins (i.e. ask the patient where the pain is coming from, as this may not always be the wound itself)
- > Details of the pain and its effects, both physical and psychosocial. For example, what does the pain feel like — is it burning, stinging, throbbing, stabbing continuous or intermittent? Do certain physical or environmental triggers exacerbate or alleviate the pain, i.e. the cold or heat, elevation or dependency in the morning/at night, etc? Psychosocially, pain can affect a patient's social life, relationships, work, and overall wellbeing (Mudge et al, 2008).

Nurses should also use a pain scale (see details below), as well as recording the patient's vital signs, any current or previous analgesia, and any side-effects of current or previous pain medication (nausea, constipation, etc) (Coulling, 2007).

The World Union of Wound Healing Societies (WUWHS, 2008) has highlighted some useful tips with regards to pain in wound care (Table 3), as well as looking in detail at the two types of pain, nociceptive and neuropathic:

- > Nociceptive pain: the body's natural physiological response to a painful stimulus, which may involve acute or chronic inflammation
- > Neuropathic pain: arises as a result of disease or damage to the nervous system.

As said, the psychological and emotional aspects that can result

**Top tip:**  
In general, it is important that wounds are kept moist to facilitate healing and aid dressing removal and prevent trauma.

**Table 2:** Therapeutic activities that nurses can use to manage wound-related pain

Activity	Practical example
Develop and promote a sense of trust and security with your patient by demonstrating competence	Be welcoming and introduce yourself with a professional yet relaxed demeanour
Be aware of non-verbal and verbal communication – use reflection to improve this and learn to create a positive patient experience	Develop a relaxed yet confident attitude; use positive and reassuring body language
Use metaphor and humour to help relax patients	Demonstrate humour with a smile, a gentle laugh, sharing a positive experience or joke
Create a sense of closeness and partnership with the patient	Provide reassurance through active listening and eye contact
Manipulate the environment for patient comfort	Make sure the room is warm and establish patient comfort on their terms, ensuring privacy and dignity

from having a chronic wound, such as anxiety, depression, can impact on how a patient perceives their pain (Vuolo, 2009), and, indeed, lead to non-concordance with treatment.

Bechert and Abraham (2009) referred to the importance of evaluation and the need for nurses to clarify the type of pain the patient is experiencing. They identified four key categories related specifically to wound pain, namely:

- > **Background pain:** this is directly related to the underlying aetiology of the wound. It can be continuous or intermittent and can be experienced even when the individual is at rest, for example pain from an ischaemic/arterial leg ulcer
- > **Breakthrough pain:** this normally occurs very quickly with a severe yet brief duration and can occur with normal daily activities, such as movement. An example would be the pain felt after recent surgery or from a

traumatic wound

- > **Procedural pain:** this results from a physical intervention in relation to managing a wound, such as removing a dressing; cleansing a wound and reapplying a dressing; dressing a pressure ulcer or leg ulcer; or the application of negative pressure wound therapy (NPWT)
- > **Operative pain:** this is related to a specific intervention performed by a specialist requiring a local or general anaesthetic, for example wound debridement, 'washout' or tissue/wound biopsy.

Whatever the source and category of pain, nurses must prepare and reassure patients, while also keeping them continually informed and, where possible, help them to be involved in the treatment regimen, as this can potentially help to alleviate pain and anxiety (Solowiej and Upton, 2012).

Nurses working in primary care should actively involve other

**Table 3:** General practice tips for pain management

- > Assume all wounds are uncomfortable, distressing and potentially painful
- > Over time wounds can become more painful, and this, along with past experience, can potentially exacerbate wound pain. Do not assume that if a patient has had a wound for some time, even years, that they have adapted to that pain or can manage it without appropriate support or intervention
- > Understand that the skin surrounding the wound can become sensitive and painful; for some, this pain is worse than the wound itself
- > Understand that for some patients the slightest touch or even exposure to air can be profoundly painful; find what best suits them in terms of dressing regimen, cleansing, skin care and bandaging
- > Know when to ask for medical intervention and when to refer for specialist assessment, for example, advice from the medical or pain management team

> **Practice point**

Pain diaries are also a useful and personal way of gaining an account of how a patient rates their pain both during daily activities and at dressing change (Upton, 2014).

members of the multidisciplinary team when trying to find the cause of wound-related pain. If infection is suspected, it is good practice to obtain a wound swab, along with routine blood tests such as full blood count (FBC) and C-reactive protein (CRP), as well as clinical observations such as blood pressure, blood glucose level, temperature, pulse and respiration for any new patient. These baseline figures should be taken routinely throughout the patient's wound care pathway. Hofman (2006) highlights the use of the four 'I's' as a useful way to think about causes of pain and the dressings and treatments to be considered (Table 4).

**Pain scales**

Butcher and White (2014) canvassed an expert panel of clinicians to understand which pain assessment tools they generally used. There was consensus that the visual analogue scale (VAS) (where patients mark their pain on a range of 1–10, with 1 signifying the least amount of pain and 10 the highest) is used 'always' or 'most of the time'; while the Wong-Baker Faces pain rating scale (Wong and Baker, 1988) (where patients are asked to pick the facial graphic that most accurately reflects their pain) is used more occasionally. Whichever scale is chosen to assess pain, it should be used consistently (European Wound Management

Association [EWMA], 2002) and considered alongside the nurse's clinical expertise and patient opinion.

**MEDICATION**

In terms of wound-related pain, the use of medications such as paracetamol, non-steroidal anti-inflammatory drugs (NSAIDs), and minor opioids on the analgesic

ladder (for example, codeine and the 'gold standard' opioid, morphine), should all be considered together with the patient's past and current medical history, the nature of the pain, and, following assessment, what best suits the individual patient.

Gaining consensus among the multidisciplinary team is vital, as everyone needs to work together and communicate regarding pain management. Furthermore, it should be remembered that what works for one patient is not guaranteed to work for the next. Thus, nurses need to take into account all the options.

Nitrous oxide (Entonox®) can also be used during dressing changes with appropriate training. Most pain management teams have access to, or can share resources relating to training for Entonox management.

### Non-pharmacological interventions

Although evidence relating to the value of non-pharmacological

interventions, such as complementary therapies and meditation, promoting wellbeing in wound-related pain is sparse, when used correctly and in conjunction with medical and nursing advice, they can be beneficial to those patients wishing to include them as part of their overall treatment plan (Richardson and Upton, 2011).

For example, in the author's trust, complementary therapy (such as massage) is used alongside conventional medical and surgical wound therapies, particularly for chronic, traumatic or malignant wounds. It is especially popular with younger adults and the paediatric population.

### DRESSING SELECTION

Dressing changes have been cited as one of the most painful aspects of having a wound (EWMA, 2002), with one international survey finding that up to 62% of participants experienced pain up to two hours after the procedure (Price et al, 2008). Thus, it is important

### > Practice point

Successful assessment and management of wound pain, as well as any associated stress, can promote a positive patient experience and potentially improve wound healing outcomes (Solowiej, 2010).

that nurses choose dressings that are atraumatic, both to the wound and periwound skin, and pain-free on removal (e.g. soft silicone dressings). This will help patients to view dressing changes as a positive part of the wound care regimen, rather than a procedure to be feared and cause anxiety.

Negative experiences from dressing changes in the past can also affect how patients' experience them in the future (EWMA, 2002), and lead to anticipatory pain (Solowiej et al, 2010). Creating a positive, relaxed environment and taking a sensitive approach to positioning the patient, with care being taken when moving painful limb(s) for instance, can be therapeutic and help to lessen any patient anxiety towards the procedure (Hollinworth and White, 2006; Richardson and Upton, 2011).

It is also important that patients are fully informed about the product used, including the rationale for choice, its mode of action, and the frequency of dressing changes. Involving patients in the decision-making process helps to ensure patient-centred care.

The majority of advanced wound care dressings have been designed with the concept of moisture balance and this, if used correctly, should ease the process of application and removal. However, dressing choice should always be guided by the condition of the wound, for example the volume of fluid being produced, bacterial load, etc.

There is the potential for wound dressings to adhere or become stuck to the wound bed which can

**Table 4:** The Four 'Y's' (Hofman, 2004)

Causes of pain	Dressings/topical regimens to consider
Infection	<ul style="list-style-type: none"> <li>&gt; Does the patient require systemic antibiotic therapy or can the infection be managed topically with antimicrobial dressings (e.g. iodine, honey, silver – note, all these products have the potential to cause some pain and should be monitored closely for tolerance and effectiveness)</li> <li>&gt; Advise trying a small patch of dressing before full application</li> </ul>
Inflammation	<ul style="list-style-type: none"> <li>&gt; Hydrogels, either in gel form or gel sheet, can be placed in a cool area or fridge before application to ease pain and inflammation</li> <li>&gt; Topical anti-inflammatory treatments or oral non-steroidal anti-inflammatory drugs (NSAIDs)</li> </ul>
Ischaemia	<ul style="list-style-type: none"> <li>&gt; <small>Check Doppler reading and refer to vascular department if required</small></li> <li>&gt; If patient has diabetes and infection is suspected, urgent podiatry and vascular department input is required</li> <li>&gt; Avoid applying pressure to the area</li> <li>&gt; The wound should be kept dry using a non-adherent dressing to avoid pain and reduce moisture until the source of ischaemia is identified and the area revascularised if possible</li> <li>&gt; <small>Observe and monitor dressings and/or bandages to ensure they are not causing</small></li> </ul>
Iatrogenic (induced pain)	<ul style="list-style-type: none"> <li>&gt; damage. Before removal ask the patient where the wound is and avoid this area if possible, or use adhesive removal spray/wipe if suitable</li> <li>&gt; Allow time for dressing removal, cleansing and changing. The patient may also want to be involved with dressing removal if it eases the pain; this involves fully explaining the procedure, using gloves and making sure the necessary hand hygiene steps have been taken</li> <li>&gt; Consider analgesia before dressing change and/or 50% nitrous oxide and 50% oxygen (Entonox ; BOC)</li> <li>&gt; Consider patch testing</li> </ul>

traumatise the wound, causing pain and potentially reverting the wound and healing back to the inflammatory phase (EWMA, 2002).

One practical tip to consider is that wounds generally need to be kept moist unless their aetiology indicates otherwise. For example, an ischaemic/gangrenous leg, diabetic ischaemic foot, or ischaemic heel ulcer should be kept dry until a full vascular assessment of the arterial blood supply is completed. The concept of moist wound healing means that the wound must be neither too wet nor too dry – applying a dressing that facilitates moisture balance will help with pain levels and ease of removal (WUWHS, 2008). However, the volume of wound fluid produced is not static, but will change throughout the wound's life cycle. Thus, it is vital that this is assessed at each dressing change, so that dressing choice can be changed to provide the optimum wound healing environment.

## CONCLUSION

Pain is a hugely important but complex area of wound management. It is possible that nurses might be under daily constraints, such as caseloads and time pressures, to cope with the intricacy of pain management and

the factors involved. Establishing a good rapport with the patient and setting time aside to discuss the impact of the wound and any related pain is a good place to start.

Management of pain in wound care is a partnership between the patient and healthcare team, where all parties share the same goal of alleviating or preventing pain. **WCT**

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## > Practice point

Nurses working in primary care should actively involve the patient's GP practice and associated multidisciplinary team when a diagnosis of any wound-related pain is required.

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## > Wound pain facts...

- > Pain is both complex and subjective
- > Patients who have experienced painful dressing changes may become anxious about future experiences
- > Assessment should involve talking to the patient about their pain and observing responses
- > Using appropriate analgesia at the correct time, selecting dressings carefully, and spending time talking to patients about their pain are all strategies that can help to reduce or eliminate pain.

# Smoking behaviour and interaction: the observation process in research

Jemell Geraghty

## Abstract

To those starting off on the research journey, the term 'qualitative research' can often seem a daunting prospect. The world of research methodology and theory is emerged in a rich history of its own terminology, meanings and experiences. Research and innovation are integral parts of the nurse practitioner's role, yet many have little understanding of the theoretical frameworks and methodologies surrounding the vast areas of qualitative and quantitative research. As part of a doctorate, the author undertook a small qualitative study, choosing her own method and question. Intrigued by the phenomenon of smoking addiction, she observed the behaviours and interactions of people who smoke. The focus of this article, however, is the process by which the study was carried out, rather than the observations themselves. This paper presents observational research from the perspective of a nurse practitioner embarking on a journey with qualitative designs.

**Key words:** Qualitative research ■ Smoking ■ Participant observation ■ Fieldwork

Smoking used to be fashionable, glamourized by models, movie stars and pop icons. It inspired an instant bond among strangers, who could suddenly be found interacting and chatting while smoking. In time, however, public knowledge surrounding the health detriments of smoking increased and the public soon began to frown on the habit.

In 2007, the smoking ban came into effect in England, prohibiting smoking in all indoor public places. Still, despite the general disapproval from society, many people who smoked at that time have persisted with their habit. The researcher was intrigued by the reasons for people continuing to engage in this addictive behaviour after all of the health promotion and controversy surrounding it. She wished to delve deep into the interactions and behaviours of smokers to observe whether there were any common characteristics among the participants, and whether this has possibly influenced their smoking addiction.

However, what was of greatest interest to the researcher was the process by which she gathered this information. This

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is the primary focus of this article, which aims to address the question: 'What is the qualitative research process involved in the case of observing smokers' interactions and behaviours?'

To fully understand how and where to conduct this research, informal networks were established with friends and colleagues to identify the best places to observe smoking, and also how the researcher could conduct this observation in a way that did not interfere too much with the participants or their smoking. This observation took place on a busy Saturday morning and afternoon in a well-known coffee shop in a town north of London. The observation lasted a total of 2 hours, and the field notes and illustrations were documented by hand at that time to ensure no information was lost. However, the full analysis of the observations will not be presented in this article, as its primary aim is to explore the process by which this information was gathered.

Once the fieldwork of this study was complete and the researcher began the analysis, it became evident that the structure of the design was basic; there were weaknesses and improvements to be made. Essentially, this is the process of qualitative research; undertaking a design, reflecting on it and learning through the process for further studies. This paper demonstrates the value of qualitative research in studying the behaviours and interactions involved with smoking addiction, and how a novice researcher might go about exploring and understanding this phenomenon. It achieves this through a discussion of research methods followed by a critique of the observational study undertaken by the researcher. It provides a reflexive account of the study in relation to the skills used, the conduct of data collection, and the performance of fieldwork, attempting to identify strengths, weaknesses and any improvements that could have been made. It also aims to demystify the research process, the interactions between researcher and participants with reference to how rapport was established, an understanding of ethical issues and confidentiality, and an awareness of some of the problems encountered.

## Qualitative research

Qualitative research is a process by which researchers can gain a unique insight, understanding and critical reflection into the processes that shape the social order, simply by applying intelligent common sense. Social research is about understanding people, the ways in which they behave, and how they interpret the world around them. It captures what people see and understand about their surroundings, how this impacts their behaviour and interactions, and in turn, how their actions are perceived by others (Wilkinson and Birmingham, 2003).

Schratz and Walker (1995) indicated that our inclination with qualitative research is to seek to understand situations as participants see them, rather than as theory suggests, and to acknowledge that once we begin to examine them, we inevitably become part of the situation. Willig (2001) suggested that the objective of qualitative research is to describe, and possibly explain, events and experiences; however, never to predict them. Therefore, in essence, qualitative research helps us as researchers to understand the nature, strengths, and interactions of variables; it can address causation and involves observation and interpretation of events (Black, 1994).

A qualitative approach, such as observation, is more revealing when the variables of greatest concern are unclear; the success of a qualitative method is greatest when the subject of study cannot be controlled and is poorly defined. This relates to the research question of this study in that the behaviours and interactions of smokers cannot be controlled and are difficult to define. Qualitative methods have the capacity to reveal what is going on without attempting to measure how often an event or association occurs. Morse (1992) revealed that becoming engrossed in qualitative research is motivating and insightful. Although the process may be filled with traps that trip the naive researcher, the rewards are immense as researchers recognize participants of their studies as real people. Qualitative research lacks predictability as the researcher cannot foresee the results. This uncertainty may be disconcerting for novice researchers; however, it removes any sense of boredom and routine from the research process.

Hickson (2008) explored the philosophy behind qualitative design, recognizing that with qualitative methods, there may be more than one world view with different researchers interpreting the data in different ways, with qualitative research providing a much more comprehensive view, including information that cannot be reduced to numbers. Qualitative studies involve a constant interchange between collection and analysis that produces a steady growth of understanding; you collect information, review it, collect more data based on what you have found, and then again analyse what you have discovered. This method can be difficult, demanding and not always a tidy process, where every step needs to be complete before moving on to the next (Walliman, 2006).

Sofaer (2002) suggested that the openness in structured, qualitative research relates not to what you want to learn, but rather to what you actually do learn in remaining open to surprises. In the case of this study, the researcher wished to focus on exploring, understanding and discovering what could be learnt from the process, rather than forcing answers to the research question, and the element of surprise was welcomed throughout the study. A detailed layout of the observational study is presented within a 'coffee shop' illustrated in *Figure 1*.

Overall, this paper aspires to reveal an understanding of the methodological theory surrounding the research process of the question: 'What is the qualitative research process involved in the case of observing smokers' interactions and behaviours?' with knowledge of the methodological literature.

### Naturalistic approach

To establish the foundation for the research question from a theoretical perspective, a naturalistic approach using observation was chosen. The naturalistic approach to research is strongly associated with the disciplines of anthropology and sociology, and is suitable for researchers who wish to understand the experiences of the individuals and groups they study (Walsh, 2001). Naturalistic observation is a research method commonly used by psychologists and other social researchers. It is a technique that involves observing participants in their natural environment, as was done in this study as the smokers were in a natural environment where they could legally smoke if they wished.

Naturalistic research is often used in situations where conducting laboratory research is unrealistic or would unduly affect subjects' behaviour (Sarantakos, 1998). This is why a coffee shop was chosen as the location for this study. The participants could be at ease in their environment, and the researcher thought this would be the best way to capture the true behaviours and interactions of smokers.

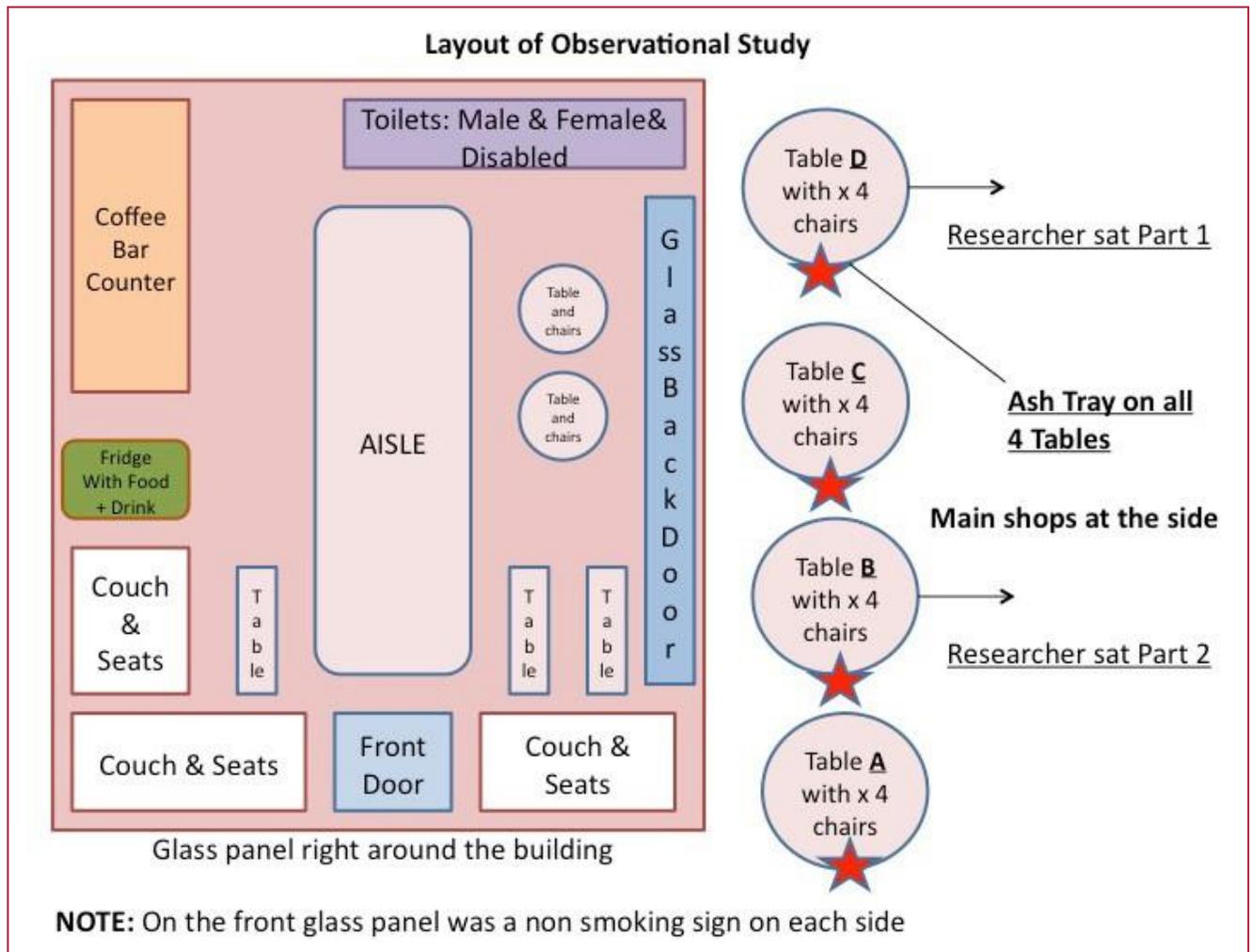


Figure 1. Detailed illustration of coffee shop; participants are identified by their tables (A, B, C, D) to maintain anonymity and confidentiality

Silverman (1985) argued that observation is not an untainted and pure activity, and that the observer may influence the setting; therefore, conclusions may be reliant and invalid at that particular time and setting. In addition, the purpose of naturalism is to observe things as they are, accepting them without question or analysis, and without making misleading distinctions between natural and artificial environments. Naturalistic inquiry stands out as an important qualitative perspective, as it places emphasis on the human as an instrument, allowing the researcher to watch, listen and make notes in an unstructured fashion, using, in the case of this study, an observational technique (Tesch, 1990).

### Observational research

This study was undertaken using a semi-structured observation, as it had no set approach except for the structure in relation to the choice of setting. Before making the decision to conduct the study in a coffee shop, informal enquiries were carried out investigating where people commonly go to smoke on a normal day, when not at home or at work. This was done in an ad hoc manner, with the researcher asking colleagues and friends who were smokers. The main reason for this was to have a structure in place with regards to a setting to increase the richness of the data. Thomas (2009) explained unstructured observation as: 'Where you get on the stage,

take part, record from the stage and watch from there.' This described what was done by the researcher in this study well.

Green and Thorogood (2004) reported that the strength of observational methods lies with the provision of data on phenomena, such as behaviour. It aims to understand the phenomenon itself, rather than people's accounts of it, and their study (Green and Thorogood, 2004) cited this as the gold standard of qualitative methods. Observational research depicts the subtle changes within social research, such as behaviour and interaction. It essentially involves understanding the routine and ordinary everyday experiences with provision of raw data, which can produce findings just as substantial as those derived from other methods (Silverman, 1993).

The method of observation challenges the researcher and can be the most difficult form of inquiry to apply to one's own environment. It relies on the researcher's own experience, intuition and analytical abilities, with challenges such as making field notes, determining what to note, and implicitly what to observe in the first place (Tjora, 2006). Adler and Adler (1998) highlighted that one of the main criticisms directed towards observational research lies in the area of the validity and reliability of results, as observers are forced to rely predominantly on their own perceptions without statistical results to confirm the significance of observed patterns or trends. However, as Selltiz et al (1976) pointed out, one of

the main reasons for using observational study is the insight it gives into behavioural patterns; this descriptive material not only provides information concerning types of behaviour in relation to different situations, but also aids in the selection of problems and hypotheses.

Silverman (1993) added that, in relation to human behaviour, observational research can combine insight with rigor in the provision of raw valid data. Clarke (2009a) highlighted that researchers using observational methods share the common belief that human behaviour and interaction is socially created and governed by social rules and norms. Therefore, to understand and learn from society, we must be part of it and examine it in its naturally occurring setting. Clarke (2009b) further added that qualitative observation can make significant contributions in generating original knowledge and understanding human behaviours in health research.

Ruane (2005) emphasized that, of all the data collection techniques available to the social researcher, field studies have the most appeal, as it essentially involves 'people watching'. Field researchers maximize the understanding of social phenomenon by actively seeking out interactions with specific people or in specific locations. In entering the natural setting of the social phenomenon, the researcher must immerse oneself in the field and must decide on the level of involvement to be adopted. For the purpose of this observational study, the researcher recognized the advantages of becoming part of study. As she was a smoker at the time, she could participate by smoking; however, this meant she became, to some extent, part of the research question itself.

### Observer as participant

To study the daily behaviours and interactions of smokers in their raw state, the researcher felt observation was the most effective way of gathering information while remaining inconspicuous, yet still part of the study. Although the researcher did interact and verbally communicate, at one point during the study, it is fair to say this participation was not full and that the researcher was an 'observer as participant' or 'partial observer', rather than a participant herself. Hansen (2006) explained that, unlike observation without participation, participant observation involves experiencing events and situations from within. Participant observation involves engaging in the activity being studied and talking with participants instead of standing off and observing from a distance.

Sanders and Liptrot (1994) added that participant observation can be an appropriate way to observe activities that the researcher is already involved in, without being too disruptive to any action that is already in progress. It can, however, cause role tension and observer effects, meaning the actions of those being observed can change as a result of being observed. It is not possible to guarantee that the presence of an observer has no effect on participant behaviour, however, it is important that the researcher acknowledges the inevitability of observer effects and features this in the data collection.

### Observing behaviour

Slife and Williams (1995) explained that human behaviours do not just happen; rather, they are a result of stimuli

or reinforcements that become interconnected with the behaviour in a precise way. The influential power behind behaviour is in the stimuli and what reinforces it; for example, the external environment. Some behaviourists have argued that, once the environmental causes of our behaviour are known, we can use this to control our own lives. When observing patterns of behaviour, the researcher should possess the correct attitude or state of mind to carry out a successful study involving human behaviour.

Rosnow and Rosenthal (1996) discussed how qualities, such as enthusiasm, open-mindedness, confidence in one's own judgement, and consistency and attention to detail, can impact on the success of a behavioural observation. The task of observing behaviour was described in terms of what was done by the observer and the observed. Observing people can vary behaviour in terms of individual judgements about the actions of others; when observation coincides with what we expect to observe, this feedback provides the ultimate validity in relation to our observation. When unpredictable outcomes occur, the feedback informs us that we do not comprehend the intention or meaning of other people. In observing behaviour, it is believed that knowledge and understanding will be found in regularities in the observation results (Sackett et al, 1978). Silverman (2005) explained that, with qualitative research, it is important to ask how and when, but also to put aside or avoid 'why' questions while studying what is ordinary, mundane and routine.

The role of participant observer can be stressful, especially if the observer is concealing his/her identity, as was the case with this study. In this instance, the researcher had to play the role of a smoker, and behave and interact according to the norms of the setting, which may not always be easy, especially if they conflict with the observer's norms (Whitley, 2002). Fortunately, in the case of this study, the researcher was already a smoker, and therefore had insight into the roleplay, and was less conspicuous to the participants around her. The researcher also made the decision not to reveal what she was observing to participants if asked, as disclosing that their interactions and behaviours were being observed would have undoubtedly affected the study. However, this never became an issue as the researcher was never asked what she was doing at any point during the observation.

Rosenblum (1978) eloquently described informal observations of behaviour as follows: 'At the beginning, the observer must simply watch, allowing individual subjects to arise as separate entities in the group and behaviour patterns to emerge as figures against the background of initially amorphous activity'. One motive for undertaking this research question was to examine the common traits among smokers and to examine whether they were completely detached from one another or whether in some way, they were interlinked in the act of smoking. This would ultimately tie into the question of whether common behaviours and interactions of smokers exacerbated the process of addiction.

### Ethical considerations

Field experiments and covert or disguised participant observation, as was used in this study, present the most ethical risk with regards to informed consent. With this type of study,

the desire to observe the participants' spontaneous and natural behaviour is incompatible with gaining informed consent; to obtain consent would destroy participants' naiveté, defeating the purpose of the study. Whether such research is looked upon as unethical depends, for some people, on other ethical concerns, such as the invasion of privacy and risk of harm (Singleton et al, 1993).

As this paper was a doctorate learning assignment and aimed to present the process of observation rather than the observations themselves, ethical approval was not required. Privacy, anonymity and confidentiality was maintained at all times during the study, and this was possible by initially describing the participants in relation to age and gender, and then categorizing them according to the tables at which they were seated, by labelling the tables as A, B, C, and D (*Figure 1*). This allowed the researcher to preserve confidentiality and anonymity throughout the study, while still maintaining the ability to efficiently identify who was being observed.

Walsh (2001) explained that a research study should do some good or be of benefit to participants. Research should not be undertaken simply for the sake of it or to promote the career or status of the researcher. The researcher felt that the study would produce a positive contribution both for the researcher, in developing as a novice observer, and also for the participants, as it aimed to reveal some common behavioural patterns in smoking, which could lead to further research in relation to smoking and addiction.

Rosnow and Rosenthal (1997) stated that, in terms of ethics involving behavioural research, there is a moral obligation not to do physical or psychological harm to the participants and to do beneficent research that is likely to produce constructive results. The motivation and meaning for researchers to operate ethically is partly a matter of professional integrity. Researchers should be committed to discovering and reporting things as faithfully and as honestly as possible, without allowing the enquiry to be manipulated by matters other than what is factual (Denscombe, 2002).

### Critique of the observational study

After reviewing this study initially, and then again after some time in conjunction with other observational studies, the researcher felt that, overall, there were many strengths and weaknesses, and that there was much to be learnt from this piece of work. As might be expected, the initial feeling around this for the researcher was one of disappointment and frustration. However, the advantage of being new to the process of research is that critiquing one's own work and suggesting improvements is not as laborious or painful as it could be if the researcher was an expert (although these thoughts may always present, regardless of how advanced a researcher is). As a novice, the researcher came to feel receptive to improvement, and criticism was welcomed as a tool for future development.

### Strengths

When exploring the literature in relation to the research question, one particular article stood out from the rest, which was used as a baseline for completing this study. The article by Tjora (2006) proved fundamental in preparing

the novice researcher for the proposed study and, indeed, the researcher's first observational study. It outlined the difficulties and challenges surrounding field research, and gave clear guidelines and examples on observational techniques, covering areas such as what to observe and how to make field notes, as well as outlining different modes of observation.

The paper was insightful and demonstrated comprehensible language and meaning to the researcher. As Tjora (2006) importantly highlighted, taking field notes is the foundation of ethnographic research; however, this key responsibility is hardly covered in the research methods literature. Novice researchers in observational studies must be encouraged to undertake new research questions and, in turn, develop their methods of data collection and analysis. It is from this experience that knowledge, understanding and confidence are gained. The researcher's use of Tjora's (2006) work was a strong point in the research process and without this, the researcher would have felt overwhelmed by the terminology presented in future literature and daunted by the research process. Novice researchers should draw on existing papers and resources, rather than attempting to reinvent the wheel, and Tjora's (2006) study gave the researcher of this study the confidence and encouragement to undertake the question.

The greatest strength of this observational study, however, was the enthusiasm and motivation of the researcher. Her genuine interest in the subject was the impetus for undertaking this research. A further strength was the researcher's commitment in becoming part of the study without causing a distraction to the participants. The researcher had recognized that sitting outside with smokers and not smoking, especially when alone, might raise questions among the participants. To gain an unspoken acceptance from the other participants, the researcher smoked, becoming part of the study, and protecting the authenticity of the data collected.

Another strength was the clear illustration of the observation layout, both inside and outside the coffee shop, with particular attention to detail, e.g. what was placed on the tables outside and what was surrounding the coffee shop. The layout also allowed the researcher to maintain confidentiality and anonymity of participants by identifying them by their tables, while still clearly establishing the participants for who they were. This may have proved difficult and confusing had a larger participant group been observed. Finally, handwritten field notes were made throughout the study, as this was thought to be the best way of naturally collecting the observation. If a computer had been used, this may have taken away from the observation and writing down what was observed likely appeared more ordinary and, therefore, less noticeable to the participants. Also, weather conditions were depicted throughout the study to set the scene in terms of the naturalist environment for the study.

### Limitations and opportunities for improvement

In critiquing this observational study, the researcher found that the weaknesses and limitations outweighed the strengths, providing lessons to be learnt and improvements to be made. It may have been useful to change the setting of observation, and maybe the day, as this might have varied the results. The attempt to complete a comparative study based on the time

alone failed to show any significant differences, and a much more structured and rigorous approach should have been used. While the environment chosen for observation was briefly investigated by looking on the internet and asking fellow smokers where they smoke, it might have been useful to apply a qualitative method to this question such as a questionnaire regarding where smokers commonly go to provide evidence to support this observational study. It would have provided more substance for the research question and would have supported the validity of the observation.

This process of combining two methodologies is known as triangulation; by using and combining different research methods, the researcher can compare results to lend validity to the research question (Dunne et al, 2005). Triangulation involves the practice of viewing things from more than one methodological perspective, so that the researcher has a better understanding of the research question.

The observation was well-timed as it took place on a Saturday during busy hours when many people were in town. However with hindsight, more time should have been given to observe the participants, possibly with a less strict approach as things may have been missed owing as a result of concentrating too much on the time aspect.

It is difficult to illustrate bias in an observational study, as replication is not easy. The group and/or its environment will have changed over time, as would the effect of a different observer depending on, for example, whether or not they were smoking (Shipman, 1997). The researcher also feels there may have been a subconscious bias on her behalf, as she smokes, and despite her good intentions, this may have impacted the observations of the interactions and behaviours recorded.

Regarding the researcher's field notes, what questions she posed, what was relevant to observe and document, and her overall preparation, the following examples demonstrate further opportunities for improvement:

- There were many 'why' questions posed by the researcher, which in hindsight only led to suggestion and could have misinterpreted the results. For example, the researcher made presumptions such as: 'Out of the remaining three tables they sit...(why was this so?..possibly a common thought that smokers sit together).' This was unnecessary
- The naivety of the researcher was evident in her decisions about what to include. For example: 'The observer realised that she has not noticed when the cake was eaten.' It did not matter if the cake was eaten or not, as it did not influence the interactions of the smoking participants. The study also mentions: 'The researcher then waits a few minutes...again at no point does any of the staff from the shop come outside during the second observation.' This highlights that the observer is speculating on actions that have not happened.

Although the study did reveal some fascinating common characteristics including age, gender and mannerisms or body language, it could be argued that the observer focused too much on what she thought she should be observing, therefore overlooking other important factors of the observation.

## Conclusion

Overall, the researcher has learnt a great deal more from critiquing her study and researching the literature around this

than the study findings. The critique highlighted areas that need to be developed, while also encompassing the enthusiasm and motivation of the researcher. The research question may not have been answered to the full extent; however, the process of observational research has been demonstrated from a novice perspective, and from that point hopes to encourage other nurses to journey on the path of nurse researcher. **BJN**

*Conflict of interest: none*

*14 March is No Smoking Day. For advice on quitting smoking visit <http://smokefree.nhs.uk/>*

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## KEY points

- Qualitative research provides rich insight into ordinary daily experiences
- Observational research plays an important part in understanding the behaviours and interactions of smokers
- Research should be embraced by nurse practitioners as a fundamental way of developing the role within health research, innovation and development
- The process and theory surrounding the methodology in research is pivotal in developing a successful research question



REC No: 14/LO/0086

Letter of Invitation: Gatekeeper

Version 03 Date: 07/08/2013

UH Protocol Number: HSK/PG/NHS/00140

**Centre for Research in Primary and Community Care (CRIPACC)**

University of Hertfordshire

Hatfield

AL10 9AB, UK

Telephone +44 (0) 1707 284000

Fax +44 (0) 1707 284115

Mobile:

Email

**Study Title: Exploring the experiences of intravenous drug users who live with leg ulceration**

Dear \_\_\_\_\_,

I am a student conducting the above research on the Professional Doctorate in Health Research at the University of Hertfordshire. I would be grateful if you were willing to facilitate the initial participant contact process. I request that all practitioners who come into contact with current or former intravenous drug users who have current or healed leg ulceration be made aware of the study and those patients who meet the criteria for the study are invited to participate.

I have attached the Patient Information Leaflet version.....date..... to this letter. If the patient appears interested in taking part then I would be grateful if you would contact me by phone or email to discuss this further. Once I meet with the potential participant to explain the nature of the study and what is asked of them, they will have one week to decide whether they wish to participate. They do not have to take part in the study and if they do they can withdraw at any time without their care or legal rights being affected.

The study requests participants to complete a diary over 4 weeks. After this time the diary will be collected from the clinical area/department/environment where the participant has their leg ulcer dressed. Participants will be then invited to a semi-structured interview after completing the diary to explore some of the issues they may have discussed in the diary. The interview will be no more than one hour long and I ask that this takes place in their

REC No: 14/LO/0086

Letter of Invitation: Gatekeeper

Version 03 Date: 07/08/2013

UH Protocol Number: HSK/PG/NHS/00140

clinical area/department/environment to ensure an atmosphere of comfort and safety. The data collected will be confidential and anonymised and stored securely and destroyed in compliance with local NHS research governance requirements. If participants agree I will also inform their General Practitioner of their participation.

Approval for the study has been granted from (name of ethics committee), ref no (insert), and from (name of Trust)

Thank you for your consideration and please contact me if you want to discuss this further.

Yours Sincerely:

Jemell Geraghty

Mobile: [REDACTED]

Email: [REDACTED]

---

**If you have any concerns about how this study is being carried out please contact:**

Dr Tricia Scott  
Senior Lecturer DHRes

Dr. Angela Dickinson  
Senior Research Fellow

Centre for Research into Primary &  
Community Care  
University of Hertfordshire  
College Lane Campus  
Hatfield

**General Enquiries Number:**

Tel: 01707 284000

If you agree your General Practitioner will be informed that you are taking part in this study.

## WANT TO KNOW MORE?

APPENDIX 7

### Please Contact

Jemell Geraghty - Tissue Viability Leg  
Ulcer Nurse, Researcher

Royal Free NHS Foundation Trust; Pond  
Street Hampstead. London. NW3 2QG.

Email: jemelldiaryresearch@yahoo.com

Number: 07580 348 121

*I am here to answer any  
questions you might have*

### Talking about your feelings

When you complete your diary you will be asked to describe your thoughts, feelings and emotions around situations that are connected to your experience of having a leg ulcer. Emotions or feelings may emerge when you recall or discuss an experience and you only need record what you feel comfortable with. I will be available to answer any questions that you may have.

# Leg Ulcers

**My** Journey  
**My** Experience  
**My** Story

Information about the study



*Please take the time to read this leaflet as it is important to understand why this study is being carried out and what it involves. Any queries regarding this leaflet please contact me: **Jemell Geraghty** by phone text or email. Contact details which appear on the back of this leaflet.*

Thank You

## WHAT IS THIS STUDY ABOUT?

My name is Jemell and I am a nurse by background and currently a student at the University of Hertfordshire where I am undertaking a Professional Doctorate in Health Research. I am exploring the experiences of leg ulceration. It is important that the people who care for you learn from your experiences. In order to do this we need the help of patients like yourself who have or have had a leg ulcer to share your experience of care and of living with a leg ulcer.

## WHY AM I BEING ASKED?

I would like to involve anyone who has ever had an ulcer or wound on their leg as a result of injecting drugs or a history of injecting. There is not much known about how people who have used or are using drugs live with leg ulceration. I want to know how you manage your leg ulcer and how your leg ulcer has affected your life.

## WHAT DOES THE RESEARCH INVOLVE?

### This project involves two types of research.

#### Diary

You will be provided with a diary that you will be asked to keep for up to 4 weeks. I will guide you so you understand how to complete the diary. You can also write about other experiences if you wish, or draw pictures if this helps your account. During the 4 weeks you will have regular contact via text/phone/email from me to remind you to fill in the diary. You can also contact me if you have any questions. I will also visit you in your local leg ulcer clinic. Any additional travel expenses to meet with Jemell for this study outside normal clinical appointments will be reimbursed - please discuss this further with Jemell.

Please avoid disclosing sensitive information that may predispose you to further enquiry in terms of criminal activity or issues relating to vulnerable adults.

#### Interview

After I have collected your diary I may then invite you to discuss what you have written. I would like to record this with your permission.

#### Where will the data be stored?

With your permission the original diaries will be stored securely in a locked filing cabinet with restricted access to Jemell only. If you wish a photo copy of your diary entries will be made for you to keep. The data from the diaries and transcripts from the recorded interviews will be stored securely on a computer which has

password security. Once the interview recordings have been transcribed and stored securely they will be deleted.

## WHAT DO I NEED TO DO?

If you would like to take part in this study then either contact me on the number provided or let your leg ulcer nurse know and they will get in touch with me.

## WHO ELSE IS INVOLVED IN THIS RESEARCH?

There will be about 15 other patients who will be involved in this research and it is completely anonymous unless you choose to discuss it with someone. The diaries will be collected by me when I visit you in the clinic.

### What will happen to my data once the study is finished?

Your name and any personal details will be changed for the study. The interview and diary transcripts and original diaries will be stored securely for 7 years and then securely destroyed.

### What will the information be used for?

The data collected will be used in my dissertation, academic papers, and academic and professional presentations.

You are free at any time to ask questions regarding this study and can withdraw from the study at any time without giving a reason and without it affecting the care or treatment provided. If you chose to withdraw from the study you will be asked whether I can use data that I have already collected.

REC No: 14/LO/0086 General Practitioner Letter Version 02 Date: 07/08/2013  
UH Protocol Number: HSK/PG/NHS/00140

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Fax +44 (0) 1707 284115  
Website [www.herts.ac.uk](http://www.herts.ac.uk)

Mobile:

Email: [REDACTED]

Date

Dear Dr.....

Re:

**What are the experiences of intravenous drug users with leg ulceration?**

I write to inform you that your patient has agreed to take part in the above research and consented to your knowledge of this. The purpose of the study is to explore the daily lived experience of current or ex intravenous drug users who live with chronic leg ulceration. Currently there is limited research regarding leg ulcer care in this group of patients. This study is part of a Professional Doctorate in Health Research (DHRes) with the University of Hertfordshire.

All that is required from the patient is to agree to complete a diary for 4 weeks and if they agree to return after the diary collection for a follow up semi structured interview. The interview should last no more than one hour. I have attached a copy of the patient information leaflet which is given to each participant. If you have any questions regarding this study please do not hesitate to contact me.

Yours sincerely

Jemell Geraghty

Chief Investigator

Student: Professional Doctorate  
in Health Research

University of Hertfordshire

Supervisors:

**Dr Tricia Scott**

Senior Lecturer DHRes

**Dr. Angela Dickinson**

Senior Research Fellow

Centre for Research into Primary &  
Community Care  
University of Hertfordshire  
College Lane Campus  
Hatfield

**General Enquiries Number:**

Tel:

## Guidance on how to complete your diary

Version 04 Date: 07/08/2013 UH Protocol Number: HSK/PG/NHS/00140 REC NO: 14/LO/0086

The aim of this diary is to record your experiences of how you live with your leg ulcer and the services and clinicians you have encountered over the course of your journey with your leg ulcer.

I would like you to keep the diary for 4 weeks. If you have any queries or if you need support then please contact me on my:

**Work mobile:** [REDACTED]

**Email** [REDACTED]

There is a list of local support services at the back of the diary if you feel in need of further support and support leaflets are also provided in your pack.

### **What should I put in my diary?**

- When completing the diary try to describe your thoughts, feelings and emotions around situations that are connected to your experience of having a leg ulcer.
- Feel free to use whatever you think best describes your experience or feeling.
- There is no right or wrong way to complete your diary as long as it represents your feelings/emotions/experience whether in a positive or negative way.
- It is normal to experience a range of different feelings when remembering or reliving an experience and you only need to record what you feel comfortable with.
- Understand that emotions/feelings may emerge when you recall or discuss an experience.

### **How should I complete my diary?**

- If you wish to use a different name when writing your diary please do so.
- You can also draw or colour using the provided markers, or stick in pictures that illustrate your experiences or emotions.
- Please record your thoughts using the pens provided.
- Please note that spelling or punctuation does not matter.
- Try to record something in your diary each day however short.
- Please avoid disclosing sensitive information that may predispose you to further enquiry.
- It is important to keep your pack containing your diary somewhere safe if you are writing about personal experiences

**Note:** Any names or places mentioned throughout this diary will be replaced with a made up name to protect your identity and that of anyone you mention when presenting and publishing the data.

Please read the additional consent form in your pack that requests permission to contact you after completion of the diary which invites you to be interviewed about your diary entries.

Thank you for taking the time to read this information..



REC No: 14/LO/0086

Version 06 Date: 03/02/2014  
UH Protocol Number: HSK/PG/NHS/00140**Consent Form for Diary Research:****Exploring the experiences of intravenous drug users with leg ulceration***Please initial the box if you agree***Researcher: Jemell Geraghty**

1. I have read and I understand the information leaflet Version 06 dated 03/02/2014 about the research that will take place.

2. I have had enough time to understand and think about whether I wish to take part.

3. The researcher has answered any questions I have.

4. I understand that it is my choice whether I complete the diary.

5. I agree that the researcher can contact me during this period of four weeks either by text/phone/email/visit to clinic.

6. I understand that I can withdraw from the study at any time without giving reason and my medical or nursing care or legal rights will not be affected.

7. I agree that comments, quotations and entries in the diary may be used in the presentation of this research and that they will be anonymised.

8. I understand that the researcher alone will have access to the diary and will keep the diary in a locked cabinet for up to seven years and understand that this will then be destroyed securely.

9. I understand that the diary transcripts will be stored on an encrypted computer with secure password access and after seven years securely deleted.

10. I agree that the researcher can inform my General Practitioner that I am taking part in this study.

11. I agree to take part in the proposed study

Name of Participant: \_\_\_\_\_ Date: \_\_\_\_\_

Signature: \_\_\_\_\_

Name of Researcher: \_\_\_\_\_ Date: \_\_\_\_\_

Signature: \_\_\_\_\_



REC No: 14/LO/0086

Version 06 Date: 03/02/2014  
UH Protocol Number: HSK/PG/NHS/00140

**Consent Form for Interview Research:**

**Exploring the experiences of intravenous drug users with leg ulceration**

*Please initial the box if you agree*

**Researcher: Jemell Geraghty**

1. I have read and I understand the information leaflet Version 06 dated 03/02/2014 about the research that will take place.

2. I have had enough time to understand and think about whether I wish to take part.

3. The researcher has answered any questions I have.

4. Following the completion of my diary I understand it is my choice whether I take part in the interview.

5. I understand that I can withdraw from the study at any time without giving reason and my medical or nursing care or legal rights will not be affected.

6. I agree that any words that I may say during the interview can be used anonymously as quotations, in the presentation of the research.

7. I understand that my comments will be anonymous.

8. I agree for the interview to be audio recorded.

9. I understand that the recording may be transcribed with the help of a professional transcriber.

10. I understand that the original recording and interview transcripts will be stored on an encrypted computer with secure password access and after seven years securely deleted.

11. I agree to take part in the proposed study.

Name of Participant: \_\_\_\_\_ Date: \_\_\_\_\_

Signature: \_\_\_\_\_

Name of Researcher: \_\_\_\_\_ Date: \_\_\_\_\_ Signature: \_\_\_\_\_

\_\_\_\_\_



**Adult Support Services within 5 miles of NW3**

**The Margarete Centre:** St James' House London NW1 2LS **Telephone:** 020 7530 3086 **Drop in times:** Mon, Wed-Thu 2pm -3:30pm and Tue 4pm - 5:30pm. Enquiries and appointments: Mon-Fri 9am - 1pm and 2pm - 5pm **Info:** The service offers a variety of treatment options for concerned drug users. It offers a group work programme, psychology service, various community detox programmes and assessment for and funding of in-patient detox and rehabilitation and complementary therapies. Contact the service for details of their facilities for the disabled. **Catchment Area:** South Camden **Referral:** GP, professional, self

**Foundation66 Long Yard:** 8-9 Long Yard London WC1N 3LU **Telephone:** 020 7404 1117 **Open:** 24 Hour Organisation. Open Bank Holidays for residents only **.Info:** This residential service is suitable for chaotic alcohol users (18 - 65 yrs) in crisis and it offers emergency admission, immediate intensive help and stabilisation. It provides an educational and therapeutic group work programme as well as individual counselling and care planning. Services offered include: Assessment, Dual diagnosis, Relapse prevention, complementary therapies. There is immediate access dependant on funding. The programme lasts up to 21 days. Clients should have no history of severe psychiatric disturbance, violence, arson. No wheelchair access. **Catchment Area:** London boroughs of Camden, Islington, Kensington and Chelsea, Westminster, Hammersmith and Fulham, Haringey, Barnet and Bromley **.Referral:** Self

**Islington and Kings Cross Foundation 66:** 130-134 Pentonville Road King's Cross London N1 9JE **Telephone:** 020 7837 0100 **Open:** Contact for details. **Info:** Foundation 66 provides a range of day care services for people who have concerns about their drinking. This includes drop-in support, access to a confidential counselling service and substance misuse support. It also provides complementary therapies such as acupuncture, yoga, reflexology and shiatsu. A women-only area is provided. This is a free service **Catchment Area:** Kings Cross and Islington areas **Referral:** Self

**Core Trust:** Lisson Cottages, 35a Lisson Grove London NW1 6UD **Telephone:** 020 7258 3031 **Open:** Mon - Fri 10am - 5pm **Info:** The Core Trust provides a structured day programme for people with drug and alcohol problems. Core Trust provides counselling and group work combined with a range of complementary therapies. **Catchment Area:** Anyone from London or outside London who is able to self fund or can receive funding for a place. **Referral:** Self, professional

**Junction Service:** 27 Station Road Harlesden London NW10 4UP. **Telephone:** 020 8961 7007 **Open:** Drop-in Mon - Fri 9.45am - 5.40pm. Open on Bank Holidays. Family Support Group Tuesday 6.30 - 8pm. **Info:** The Junction Service offers information, advice and support for those with alcohol and drug abuse problems in Brent. It also offers HIV/hepatitis B and C tests as well as complementary therapies. This service is part of Turning Point. **Catchment Area:** Brent **Referral:** The Junction operates on an agency referral and client self-referral basis. Brent

**Isis North:** 99 Seven Sisters Road London N7 7QP **Telephone:** 020 7272 1231

**Open:** Monday to Friday 9am - 5pm

**Info:** ISIS North is a direct access drug project offering information, advice and support, as well as referral into treatment services.

**Catchment Area:** North Islington - parts of N4, N5, N7, parts of N16, N19.

**Referral:** Self, or via other agency

**Camden Casa:** 75 Fortress Road London NW5 1AG **Telephone:** 020 7428 5955

**Open:** Monday to Friday from 10am to 6pm.

**Info:** CASA helps individuals and families in Camden and Islington who are affected by alcohol or other drug problems. Services include advice, information, individual counselling and support groups in a community setting. It also provides a shared rehabilitation housing service.

**Catchment Area:** Mainly Camden and Islington. Will consider clients from other areas. **Referral:** Self-referral, GP, Social Services

**Response North Camden Drug Service (NCDS):** 457 Finchley Road

London NW3 6HN **Telephone:** 020 3317 6400 **Open:** Monday 9am to 5pm.

Tuesday 11am to 5pm. Wednesday 11am to 7pm. Thursday 9am to 5pm. Friday

9am to 5pm. Lunchtime closed every day from 1pm to 1.30pm **Info:** Response is part of a range of statutory drug services in Camden, offering a comprehensive assessment, treatment and referral package for male and female clients 18 years

and older. **Catchment Area:** North Camden **Referral:** Open instant access at

NCDS for potential service users. Friends or family can drop in during opening times for assessment.

### **Addiction help – lines**

- **Alcoholics Anonymous** – For those who think their drinking is becoming a problem. Alcoholic anonymous offers the chance to talk to someone who knows the issues through personal experience **(0845 769 7555)**
- **Samaritans** - Available 24 hours a day and provide confidential support for people in emotional distress. They offer an unbiased, non judgemental service and can be contacted by telephone **(08457 90 90 90)** they also provide a face – to - face service available at their local branches.
- **Support Line** - Offers help to individuals on any issue. Provide non – judgemental, confidential support and advice to enable the caller to find ways of coping with a particular problem **(0208 554 9004)**
- **Talk to Frank** – Confidential drugs advice: If you want to talk, you can call FRANK free, 24 hours a day, 365 days a year **(0800 77 66 00)**. Need a quick answer? **Text** a question to **82111** and Frank will text you back. **Email:** [frank@talktofrank.com](mailto:frank@talktofrank.com) whatever you want to know, FRANK will tell you, no questions asked.



~ Mr Crack ~

I ask myself "What Is Jail"?

Its a place they send you when you  
don't get bail!

Locked in a room they call a cell.

Where no-one comes when you ring the bell!

Where you see your'e cellmates takin the  
piss..

Why am I in a place like this?

I blame that s-e-e-z-e-r "Mr Crack"!

He's hard to shake when he's on your  
back.

The very first blast is the only one.

But to tell you the truth he's not much  
fun.

He's got me out there committing crime.  
And now I'm in here doing time!

Mr Crack, you're nothing but evil,  
All you do, is destroy people.

I was so weak to fall for you.

And now I'm here feeling sad + blue.

Well Mr Crack, hear what I say,

Jail saved me, I got away.





Summer  
Days





THIS IS A ROUGH COPY OF HOW THEY LOOKED  
WHEN I HAD SHOWER!!



24/5/11  
LEFT LE  
BELOW  
KNEE

Thursday 10th July  
 Legs not bad. Ulcers starting to  
 'FIZZ' because I know that  
 the dressings need to be changed.

Friday 11th July.  
 Hospital - ulcers much smaller.  
 When I started this journey my  
 ulcers were as below. This change did  
 not begin until May 22nd -  
right leg      left leg      onward!  
then      now      then      now

