HEPATITIS C TESTING AMONG YOUNG PEOPLE WHO EXPERIENCE HOMELESSNESS IN MELBOURNE

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Produced on archival quality paper
Declaration of Authorship

This is to certify that:

(i) the thesis comprises only my original work towards the PhD except where indicated in the Preface,
(ii) due acknowledgement has been made in the text to all other material used,
(iii) the thesis is less than 100,000 words in length, exclusive of tables, maps, bibliographies and appendices

Signed……………………..
Preface

This thesis has drawn data and participants from an existing cross-national study - *Project i: Homeless young people in Melbourne and Los Angeles* (see Section 2.5.3. for more detail on the study). This preface outlines the division between *Project i* and the work undertaken for this thesis.

The aims, research questions and analyses presented in this thesis have not been previously undertaken or published by *Project i* in any form and, as such, represent an original contribution to the research field. Hepatitis C was included in the original mandate of *Project i*, however, given the quantity of data collected and the time needed to perform meaningful analyses, it was unable to be examined in great detail.

The two studies presented in this thesis differ in their use of *Project i* resources and the way they represent an original contribution. The first study (see Chapter 3) utilises the longitudinal dataset from the Australian component of *Project i*. During my employment on the study I, among many other roles, conducted a number of the longitudinal surveys. The research questions and data analyses performed on these data represent original work towards the PhD. The second study presented in this thesis (see Chapter 4) utilises the Australian longitudinal cohort of *Project i* as a pool from which to recruit participants. The research questions, recruiting of young people, performing the interviews and analysis of the interview data represent the original contribution of this thesis.
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Abstract

Despite the large number of hepatitis C tests performed in Australia each year and the effort expended on developing and implementing policies to regulate this practice, very little research has been undertaken on the human factors associated with hepatitis C testing. This thesis aims to: 1) examine patterns (prevalence and incidence) of hepatitis C testing among young people who experience homelessness in Melbourne, Australia, and how they relate to behavioural and contextual factors, and 2) examine the contexts in which hepatitis C testing occurs for these young people. Two studies were undertaken to address these aims. The first employed longitudinal panel surveys collected from young people who had recently become homeless for the first time (N=165) over three waves: baseline, 12-month and 24-months. The second employed semi-structured qualitative interviews 24-months after baseline with 20 young people recruited from the longitudinal cohort.

Results indicated that hepatitis C testing was a very common experience and increased in prevalence over the course of the study (14%, 22%, 32%). The average incidence rate of first time testing was 0.222 or 22% per person years. Statistical analyses revealed that seeking help for general health issues, seeking help for legal issues, staying in hospital, pregnancy and testing for HIV or STIs were important predictors of both recent and first time testing. Accessing a needle and syringe program and use of sedatives or analgesics were also significantly related to recent testing, while the use of stimulant drugs and engaging in sex-related alternative sources of income were significantly related to first time testing. Surprisingly, standardised measures of blood-borne virus risk were not related to testing in either set of analyses.

Young people’s reasons for testing were diverse and often varied each time they were tested. Four major themes were identified. The first three themes – “danger”, “safety”, and “trust” – reflected different ways in which young people positioned themselves as active and conscious decision makers in relation to testing, while the fourth theme – “circumstance” – reflected the way in which many young people did not actively seek
testing or identify a need to be tested but were, rather, only tested because of a situation in which they found themselves.

Results indicated that the characteristics of those tested and the reasons why they were tested were not in accordance with the aims and assumptions of testing policy. Large numbers of young people not scientifically deemed at risk are seeking and/or receiving testing – it instead serves a social or emotional function – and many are tested in situations with little or no choice. These patterns of testing stretch limited health care budgets and the effectiveness of testing as a component of a broader hepatitis C prevention strategy. Some young people did identify dangerous practices and seek testing as a consequence. Their retelling of danger however, did not contain elements of blame, as is often implied in health promotion and illness prevention measures. Young people were also found to be active help seekers in relation to hepatitis C, a characteristic that is typically not attributed to them because of the transitional stage of life they occupy.
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Glossary of Terms

AIHW – Australian Institute of Health and Welfare
ANCARD – Australian National Council on AIDS and Related Diseases
ANCAHRD – Australian National Council on AIDS, Hepatitis C and Related Diseases
AIPC – Australian Institute of Primary Care
ABS – Australian Bureau of Statistics
CASI – Computer Assisted Self Interview
CDC – Centers for Disease Control and Prevention (United States)
CLF – Canadian Liver Foundation
DFaCS – Department of Family and Community Services (Australia)
DH – Department of Health (United Kingdom)
DHS – Department of Human Services (Victoria, Australia)
HBM – Health Belief Model
HIV – Human Immunodeficiency Virus
NCHECR – National Centre in HIV Epidemiology and Clinical Research (Australia)
NHMRC – National Health and Medical Research Council (Australia)
NSP – Needle and Syringe Program
NSRL – National Serology Reference Laboratory (Australia)
PCR – Polymerase Chain Reaction
RACGP – Royal Australian College of General Practitioners
RNA – Ribonucleic acid
SAAP – Supported Accommodation Assistance Program
STI – Sexually Transmitted Infection
TAFE – Technical and Further Education
TPB – Theory of Planned Behaviour
TRA – Theory of Reasoned Action
WHO – World Health Organization
Hepatitis C is one of the most frequently reported notifiable infections in Australia (National Centre in HIV Epidemiology & Clinical Research, 2005 [NCHECR]) and, since it was formally identified in 1989, has emerged as a major public health challenge domestically, as well as internationally. Although the total number of hepatitis C infections reported each year in Australia has fallen in recent years (replaced by Chlamydia as the leading notifiable infection in 2001), the total number of infections and the rate of new infections is still unacceptably high.

Hepatitis C is caused by the highly infectious hepatitis C virus, which is transmitted solely via blood-to-blood contact and affects the liver. Chronic infection with hepatitis C negatively impacts upon the health and well-being of individuals infected for many decades. Although premature death, as a consequence of liver failure or liver cancer, occurs in only a small proportion of cases, the majority of those infected will experience severe and disabling symptoms, such as tiredness, lethargy and nausea. Treatment for hepatitis C – typically combination therapy of pegylated interferon and ribavirin – is now accessible to the majority of those infected in Australia, however current regimes of treatment are still only partially successful. The economic burden of chronic hepatitis C infection on the individual and society as a whole is substantial and includes lost wages and productivity through illness and accessing health care, as well as the cost of identification, treatment, management and prevention of hepatitis C infection.

The medical and biological aspects of hepatitis C infection and treatment have received considerable research attention. The human aspects of hepatitis C infection have, by comparison, received substantially less consideration; the majority of studies have focused on so-called risk factors or correlates of infection. These studies state that in developed countries such as Australia, injecting drug use represents the single greatest mode of transmission. Other factors have been implicated to lesser degrees and include blood transfusions, therapeutic injections, some non-injecting routes of drug consumption, contact with the prison system, tattooing and skin piercing, vertical
transmission, and exposure in the health care setting (MacDonald, Crofts, Wodak & Kaldor, 2001).

An important issue which has practically been ignored in the broader research on hepatitis C are matters relating to testing, in particular who is tested for hepatitis C, why are they tested and what are their experiences of being tested. Gaining a thorough understanding of the human aspects of testing is vital to developing effective strategies aimed at preventing the spread of the virus, given that many people who are hepatitis C positive are believed to be unaware of their infection status. These individuals may, as a result, unintentionally transmit the virus to others. They are also unable to receive treatment for their infection. Such knowledge is important because it can assist in the development of more tailored approaches to testing, which can potentially lead to more positive experiences and outcomes for recipients of testing and broader public health concerns (Loxley, Davidson, Heale & Sullivan, 2000).

The dearth of research on testing is surprising given that serological testing for hepatitis C is a relatively common medical procedure undertaken in the Australian health care system. As many as 1.9 million tests are performed each year (Australian National Council on AIDS, Hepatitis C & Related Diseases [ANCAHRD], 2003; National Serology Reference Laboratory [NSRL], 2004). Testing for hepatitis C is relatively easy to access in Australia and may be performed in any setting in which a medical practitioner operates, such as a hospital, medical clinic, specialist clinic or needle and syringe program (NSP). Testing is principally the domain of medical doctors but, in some circumstances, can be independently performed by nurse practitioners or community health workers. Testing for hepatitis C typically requires a small sample of intravenous blood. Saliva tests are available but are not as accurate serological testing and are generally not used. Serological testing for hepatitis C is a low cost procedure to perform – under $AU15 – which, in Australia, generally has no upfront cost to the recipient (Department of Health & Aging [DHA], 2005).

Testing is only one aspect of a broader public health response to the hepatitis C epidemic. This response has been closely modelled on HIV/AIDS policy and has
primarily focused on prevention through a harm reduction approach. Under this framework, a broad range of initiatives have been adopted in Australia, such as NSPs, methadone maintenance therapy, other forms of drug treatment and public education campaigns. Furthermore, many public health policies that regulate commercial and medical practices, such as tattooing, skin piercing and blood donation, have been developed or extended to include hepatitis C.

Policies directly relating to hepatitis C testing in Australia, and indeed those of other developed countries, outline who should be offered testing, the circumstances under which different types of tests (antibody or polymerase chain reaction [PCR]) should be used and how testing should be performed, in particular ensuring the provision of pre- and post-test counselling and discussion. In addition to a policy response, many social and health services have been established or reconfigured to target groups, for example injecting drug users, for testing. The primary focus of these policies and services is on risk factors verified through scientific inquiry to relate to the transmission of the virus and groups deemed at-risk because they engage or display these factors (ANCAHRD, 2003).

Testing, provided it is performed as intended by policy, is assumed to fulfil a number of roles. First, it provides the testee with sufficient information for an informed decision to be made about whether they wish to be tested. Second, it minimises possible negative outcomes associated with having a diagnostic test or receiving a positive test result. Third, and most importantly, it is assumed to serve a preventive function. This is primarily achieved through identifying those who are hepatitis C positive (McCoy, Watson & Kosley, 2003). These individuals can then be offered treatment and can be counselled to modify their behaviour to reduce the likelihood of transmitted the virus to others. Testing can also serve a secondary preventive role by counselling those who test negative to modify their behaviour in an effort to reduce their risk of future infection. Implied in these policies but typically not acknowledged is a single trajectory or pathway of testing, namely that those who undergo testing have made a choice to be tested, undergo testing solely for medical or health-related reasons, and/or have a desire to change the practices that have caused them to seek or require testing (Gordon, 1999).
Despite the considerable effort expended by various departments, agencies and researchers on developing and implementing policies related to hepatitis C testing, it is not reliably known whether the practice of testing reflects the aims and assumptions of these policies. The paucity of research (less than 10 studies) thus far tentatively suggests this may well be the case. These studies indicate that those who engaged in putative risk practices, in particular injecting drug use, those with better knowledge of hepatitis C, and those who have contact with health services for other blood-borne viruses, are more likely to have been tested for hepatitis C. Moreover, analysis of the reasons for seeking or accepting testing reveals they are tested because they had engaged in a practice they perceived to be risky or of concern, because of opportunity or requirement, or out of concern for other people in their life.

Notwithstanding the dearth of research that calls into question the reliability of these findings, these studies are limited in their potential to adequately explain the breadth of the practice of testing for a number of reasons. The most important of these is that the majority of research to date has examined infection and testing from an epidemiological risk framework. This research has been solely concerned with identifying factors directly associated with the transmission of the hepatitis C virus and indentifying groups of the population within which these factors cluster. This version of risk has meant that research on hepatitis C testing has concentrated on these factors for infection and those who inject illicit drugs. Although this mode of thinking has served to direct limited health care budgets to those perceived most in need or at risk, it can also implicitly blame those who knowingly engage in such practices by designating them as dangerous, socially unacceptable and, therefore, to be avoided. Individuals who engage in these risk practices are labelled at-risk and different from others. Moreover, social and contextual factors, such as employment, education, living arrangements and contact with the social service sector, have generally been excluded or ignored. These factors are, however, likely to provide valuable insight into the characteristics of those who are tested for hepatitis C.
It should be noted at this point that although the dominance of epidemiological risk is a major limitation of the current understanding and response to hepatitis C, this thesis is not principally focused on risk. The idea of risk will be discussed, as it is a central and unavoidable concept in the study of health and illness; hepatitis C testing and infection being no exception. The primary aim of this thesis is, however, to examine the practice of hepatitis C testing within the broader context of the lives of those who choose (or otherwise) to undertake testing. This aim may provide alternative and/or complementary understandings to this current body of knowledge surrounding hepatitis C, which can inform associated policies and practices and, ultimately, improve the experiences and outcomes of those who receive testing for hepatitis C.

This thesis will focus on an examination of testing behaviour among young people. The evidence currently available suggests that young people are at particular risk for hepatitis C. This is partly because it seems that they are more likely to engage in practices associated with hepatitis C infection, particularly injecting drug use. Young people, as a category, are also believed to be at particular risk because of the transitional stage of life they occupy. Young people are in a stage between childhood and adulthood where they begin to receive the rights and responsibilities of adults but are also said to lack the skills and personal resources, an adult is presumed to possess, to successfully negotiate and manage risks associated with these rights and responsibilities. As such, they are seen to be at-risk.

A group of young people who have received considerable research attention are young people who experience homelessness. Surprisingly however, very little of this research has focused on hepatitis C. Young people who experience homelessness are a paradigmatic group of at-risk young people and are typically characterised as a socially and economically disadvantaged population. They are of particular interest in the study of hepatitis C because they are more likely than home-based young people to inject illicit drugs and inject themselves in situations that increase the likelihood of engaging in unsafe injecting practices. They are also highly likely to be exposed to social and health services attempting to address the problem of hepatitis C (Mallett, Edwards, Keys, Myers & Rosenthal, 2003). Young people who experience homelessness,
therefore, make an excellent population to examine testing behaviour, as they are likely to engage in testing practices to a sufficient degree to be adequately explored in this research. Although the choice of this population seemingly contradicts preceding statements concerning the dominance of epidemiological risk to define research samples and measures, the use of this population to study hepatitis C testing does, nevertheless, shift (rather than alter) the focus on risk of previous research. In this instance, these young people are not solely defined by the practices in which they engaged (as in the case of injecting drug users) but, rather, by the broader social context they occupy.

Unlike previous research on hepatitis C testing, this thesis will examine testing behaviour among young people who have recently become homeless over time. The main advantage of longitudinal designs over cross-sectional designs is that they involve collecting data from the same individual(s) at more than one point in time. These data enable changes over time to be examined and hypotheses about cause-and-effect relationships to be tested. In addition, this research will utilise qualitative methods, namely semi-structured interviews, to also explore testing practices. This methodology allows different types of research questions to be posed and different types of answers to be obtained. In particular, these methods enable an in-depth exploration of people’s experiences, in this case their experiences associated with hepatitis C testing.

Through the use of these complementary methods – namely longitudinal surveys and qualitative interviews – this thesis aims to better understand the human factors associated with hepatitis C testing among young people who experience homelessness in a major metropolitan centre, namely Melbourne. This broad objective is articulated through two specific aims. First, this thesis will examine patterns of hepatitis C testing and how they relate to behavioural and contextual factors among young people who experience homelessness in Melbourne. In particular, it will answer two broad questions: what is the prevalence and incidence of testing among these young people and how do these measures relate to a broad range of behavioural and contextual factors. Second, this thesis will examine the social, behavioural, psychological and environmental contexts in which hepatitis C testing occurs for young people who experience homelessness. In particular, it will answer the questions, why are young
people who experience homelessness tested for hepatitis C and how do young people’s reasons for testing relate to their experience of homelessness, gender and the way they manage their health more generally.

The idea for this research emerged from a now concluded study – *Project i: Homelessness young people in Melbourne and Los Angeles*. *Project i* was a unique study in that it was longitudinal (six waves over two years), cross-national (Melbourne and Los Angeles, United States) and principally focused on young people who had recently become homeless for the first time (see 2.5.3. for a detailed description of the study’s aims and methods). The study was initially funded to examine trajectories of homelessness and how these may relate to HIV risk and infection. Due to the rare opportunity the study presented to capture the experiences of a typically unstudied segment of the population of young people who experience homelessness, it quickly expanded to also focus on other aspects of the young people’s lives, such as employment, education, patterns of drug use, housing histories and mental health.

The author’s involvement with *Project i* began when he was employed as a Research Officer in early 2001 to undertake quantitative data analyses, among other duties. During the course of the research it become evident that hepatitis C was an extremely important health issue for young people who experience homelessness, particularly those who had been homeless for long periods of time, and was subsequently reported in a letter to the *Australian Journal of Public Health* (see Rosenthal, Mallett, Myers & Rotheram-Borus, 2003). This finding sparked the author’s personal interest in the area of hepatitis C. A thorough examination of hepatitis C infection was unable to be performed due to the very low number of young people who had recently become homeless for the first time reporting a new diagnosis of hepatitis C over the longitudinal survey waves. However, it became apparent that testing for hepatitis C was a highly prevalent and important issue for these young people. It was, however, well beyond the resources of the already extended *Project i* to perform the level of analysis that this important issue demanded and, thus, this thesis was born.
Towards the end of the longitudinal study, Dr. Shelley Mallett and the author had the opportunity to extend Project i’s research on hepatitis C when a partnership was formed between the Hepatitis C Council of Victoria and a number of agencies from the homelessness service sector, including Open Family Australia and Melbourne Citymission. This partnership was charged with the task of developing and evaluating a hepatitis C prevention program on behalf of the Department of Human Services, Victoria. This project, which became known as Project Blood Oath, consisted of two research streams (Myers, Mallett, Brissenden & McNeill, 2005). The first stream focused on training frontline service providers from support and accommodation services in Melbourne with the information and skills necessary to act as sources of knowledge on hepatitis C for young people in their care. The second stream focused on piloting a street-based outreach intervention.

In addition to this experience in research on homelessness, young people and hepatitis C, which has provided a foundation from which to undertake this thesis, the author has also spoken with many practitioners and academics within the field over the course of this research. This included service providers associated with NSPs, general and population specific health services, sexual health services, and drug treatment services, as well as a number of researchers and academic staff. Although these discussions are not presented as formal methodology, they have provided insight into the context and practice of hepatitis C testing in Melbourne and have particularly aided in the interpretation of the results from the studies that will be presented here.

This thesis is organised into five chapters. Chapter one reviews the current research literature and policy documents relating to hepatitis C infection and testing, with close attention to the Australian context. This chapter focuses on the natural history and epidemiology of hepatitis C infection, research on hepatitis C and HIV testing, the principal policies relating to hepatitis C testing in Australia, the assumptions underlying these policies, and a number of limitations of the current literature on hepatitis C infection and testing.
Chapter two reviews the current literature on young people who experience homelessness and argues that one of the main ways these young people are understood is as an at-risk population. This chapter discusses the research that appears to confirm this view, with particular attention to practices that can place them at risk for hepatitis C, and the shortcomings of this research stream. Chapter two also discusses different definitions of risk, how notions of risk have shaped our understanding of young people who experience homelessness and the category of young people more generally. It then concludes by outlining the research that was conducted for this thesis.

Chapter three presents the first study of this thesis, which examines patterns of hepatitis C testing among young people who experience homelessness in Melbourne and how they relate to behavioural and contextual factors. This study uses data from the Australian component of Project i: Homeless young people in Melbourne and Los Angeles (see Mallett, Rosenthal, Keys & Myers, 2006; Rossiter, Mallett, Myers & Rosenthal, 2003). The analysis of these data focuses on the prevalence and incidence of hepatitis C testing.

Chapter four presents the second and final study of this thesis, which examines the contexts in which young people who experience homelessness are tested for hepatitis C. The analysis in this chapter focuses on the reasons young people who experience homeless are tested for hepatitis C and the ideas that inform these reasons. The final chapter, Chapter five, compares the findings of each study and discusses their implication for research and policy. The final chapter also identifies the limitations of these findings and outlines possible future directions for research in this field.
Chapter 1

Hepatitis C Infection and Testing

1.1. Hepatitis C Infection

1.1.1. Overview

Hepatitis C is one of the most frequently reported notifiable infections in Australia (NCHECR, 2005) and is quickly becoming a major public health issue. Hepatitis C is a chronic infection that impacts negatively upon the health and well-being of those infected for many decades (Rowe, Rowe & Malowaniec, 2000). It is caused by the hepatitis C virus, which is transmitted via blood-to-blood contact and affects the liver (Australian Institute of Primary Care [APIC], 2001; Crofts & Wodak, 2001; Farrell & Cossart, 1999; Sylvestre, 2003). Hepatitis C can remain asymptomatic for many years and, as a result, individuals may spread the infection without their knowledge. There is currently no vaccine for hepatitis C and only partially successfully treatment options (Gowans, 2001). The majority of research on the human aspects of hepatitis C has focused on estimating its prevalence and incidence and determining risk factors.

The hepatitis C virus was first identified in 1989 when it was found to be the causative agent in approximately 90% of cases of non-A, non-B hepatitis or post-transfusion hepatitis – an infection commonly associated with people who had received a blood transfusion (Canadian Liver Foundation [CLC], 2000; Crofts, 2001; Purcell, Alter & Dienstag, 2000; Sherlock, 1996). A test to screen donated blood for hepatitis C antibodies was introduced in Australia (Wood, Coghlan & Boyce, 2001) and many other developed countries, such as Canada (CLF, 2000), the United Kingdom (Department of Health [DH], 2004) and the United States (Moyer, Mast & Alter, 1999), the following year. Since this time, six genotypes and many subtypes have been reliability identified. Some authors suggest there may be up to eleven genotypes, however this is not commonly accepted (Krajden, 2000; Tokita et al., 1995; Zou, Tepper & Giulivi, 2000). Although there is currently little evidence of an association between different genotypes
and the trajectory of liver damage, infection with different genotypes does have implications for treatment outcomes, as some genotypes do not respond to current medications as effectively as others (Dore, MacDonald, Law & Kaldor, 2003; McHutchinson et al., 1998; Sievert, 2001; Sievert & Korevaar, 1999; Thompson & Locarnini, 2001). Furthermore, an individual can be infected with more than one genotype, further complicating outcomes (AIPC, 2001; Aitken et al., 2004).

1.1.2. Significance of Hepatitis C Infection in Australia

The annual direct health cost of hepatitis C in Australia during the financial year 2004/05 was estimated to be $156 million (Gadiel & Powell, 2005). Direct costs reflect expenses associated with action undertaken to directly tackle the effects of hepatitis C in the community. It includes $9.9 million for screening of donated blood collected by the Red Cross, $48.8 million for prevention and harm minimisation strategies, the bulk of which funds the network of NSPs across Australia, $78.9 million for general diagnostic testing and treatment, and $18.4 million for research organisations. These estimates will only increase in years to come as the total number of hepatitis C infections rise. The present estimate of this increase, excluding factors such as inflation and other changes in the cost and effectiveness of medical treatment and management, is that for every 1000 new cases of hepatitis C $13.5 million will be incurred in direct health cost over the course of the infection (Gadiel & Powell, 2005).

The annual indirect cost associated with hepatitis C infection in Australia was estimated at $32.5 million during the financial year 1996/97 (Shiell, 1998). Adjusted for inflation\(^1\), this figure was approximately $40.4 million in 2005. This adjustment however, is still likely to significantly underestimate the indirect costs, given that the population of hepatitis C positive individuals has increased substantially since 1996/97. Indirect costs reflect the loss in economic production due to hepatitis C infection and are derived from average weekly earnings, the number of work days those with hepatitis C

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\(^1\) Estimates were updated from the original publication to equivalent values in 2005 (the latest year in which adjustments could be made at the time of writing this thesis) using an inflation formula developed by the Reserve Bank of Australia (2006).
will miss, on average, in order to attend health care services directly related to the management of their infection and premature death. For every 1000 new cases of hepatitis C there is an indirect cost of up to $33.6 million over the course of the infection ($41.7 million adjusting for inflation). These estimates however, do not include losses resulting from employment absenteeism not related to accessing health care or lost productivity while at work. These sources of economic loss were not factored into the original estimates because of the difficulties in collecting such data. Subsequently, these figures may underestimate the true indirect costs associated with hepatitis C infection.

The number of people who contract hepatitis C annually, in addition to the direct and indirect costs associated with diagnosing, treating and managing those infected, make it an extremely important public health issue in Australia and many other countries around the world (Brown & Crofts, 1998; Farrell & Cossart, 1999; Shiell, 1998).

### 1.1.3. Natural History

The untreated progression or natural history of hepatitis C is highly variable. A complete understanding of the natural history and, in particular, the predictors of progression, has not yet been achieved due to a number of methodological issues (Dore, 2001; Sylvestre, 2003). These issues include a lack of studies examining acute or newly acquired hepatitis C, the lack of large-scale population studies, the typically slow progression of the infection and a dearth of longitudinal studies. Moreover, the few longitudinal studies that have been undertaken have typically focused on those who acquired hepatitis C through blood transfusions. Many of these individuals, such as those with haemophilia, however, have a high mortality rate unrelated to hepatitis C, which greatly limits the generalisability of the results (Dore, 2001).

These issues notwithstanding, the available evidence indicates that not all of those initially infected with hepatitis C will experience negative outcomes as a result of infection. The incubation or “window period” – the time between exposure to the virus and when antibodies are detectable – can range from two weeks to six months but
averages six to seven weeks (Moyer et al., 1999). Once antibodies are detectable the individual is said to have acute hepatitis C. The majority (approximately 70%) of those with acute hepatitis C will not experience hepatitis-related symptoms. The remainder will experience symptoms typical of viral hepatitis infection, including depressed mood, nausea, abdominal pain, jaundice and dark stools and urine (Marinos & Post, 2003; Moyer et al., 1999). Approximately 15-20% of people with acute hepatitis C will spontaneous clear the virus (Batey, 2003), that is, they will not have the active virus in their bloodstream, as measured by a PCR test, although they will continue to test positive for hepatitis C antibodies for some time (AIPC, 2001). Those who do not spontaneously clear the virus develop chronic hepatitis C.

Many of those who develop chronic hepatitis C do not experience negative health outcomes associated with the infection. Approximately 20-40% of those with chronic infection, although continuing to be infected, will either not develop, or display only minimal signs of, liver damage (fibrosis) or symptoms (AIPC, 2001; Batey, 2003; Dore, 2001; Farrell & Cossart, 1999; Lin, Barker & Batey, 1999). These individuals may still experience severe and disabling symptoms of hepatitis C infection that will impact on their daily life, such as tiredness, lethargy and nausea (Batey, 2003). The remaining 60-80% will develop some degree of fibrosis or symptoms and 10-20% of this cohort will develop cirrhosis of the liver. Those who develop cirrhosis are more likely to be male, over 40-years-old at time of infection, have a high intake of alcohol, or have HIV or hepatitis B coinfection. Approximately 2-5% of those with cirrhosis will progress to liver failure or liver cancer (Batey, 2003; Dore, 2001; Farrell & Cossart, 1999; Moyer et al., 1999).

1.1.4. Prevalence and Incidence

1.1.4.1. International

The last global estimate by the World Health Organization (WHO, 1999) indicated that approximately 3% of the world’s population, or 170 million people, were infected with hepatitis C. There is considerable variation in the prevalence of hepatitis C between
regions and countries. Africa and the Eastern Mediterranean have the highest regional prevalence, with infection rates of 5.3% and 4.6%, respectively. Individual countries with the highest recorded rates include Egypt (18%), Rwanda (17%), Cameroon (12.5%) and Bolivia (11.2%), while the lowest recorded are Sweden (0.003%), followed by the United Kingdom (0.02%) and Finland (0.02%). These data, however, may not accurately reflect the state of hepatitis C in some regions or countries, as data are unavailable for some countries and methodology can vary significantly between countries (WHO, 1999).

The distribution of hepatitis C genotypes also varies across the world. Genotypes 1, 2 and 3 are frequently found in many parts of the world, particularly Western countries, while genotype 4 is typical found in Central and Northern Africa and the Middle East. Genotype 5 is typically found in Southern Africa and genotype 6 in South-East Asia (Crofts, 2001; Zou et al., 2000).

1.1.4.2. Australia

The National Centre in HIV Epidemiology and Clinical Research collects data on the prevalence and incidence of hepatitis C infection in Australia through the national notifiable disease surveillance system (NCHECR, 2005). These data indicate that the prevalence in Australia is considerably lower than the global average with 1% of the population, or approximately 197,000 people (range 154,000-238,000), believed to be infected (NCHECR, 2006a, 2006b). A further 67,000 are thought to have been exposed to the virus but did not become chronically infected. Current projections indicate that by the year 2020 between 321,000 and 836,000 people are likely to be infected with hepatitis C (ANCAHRD, 2002).

During the calendar year of 2005 there were approximately 12,600 notifications of hepatitis C infection (per capita rate of 63 per 100,000). Although large, this figure represents a substantial decline in notifications since 2000, when a little over 20,000 were made (107 per 100,000). The rate of hepatitis C notifications is greatest among 20 to 29-year-olds and 30 to 39-year-olds. All age groups have displayed a decline in the
number of notifications from 2000 to 2005, however, the reduction was greatest among 15 to 19-year-olds, among whom notifications fell by approximately 68% (compared to 47% for 20 to 29-year-olds). The general decline in the number of notifications may reflect a decline in the actual number of new infections and/or a decline in the population of those who have been infected for some time but are unaware of their infection. The substantial decline in notifications, particularly among 15 to 19-year-olds, suggests declining incidence of new infection among young injectors and possibly, the success of public health strategies targeting those who inject drugs (NCHECR, 2006a).

Notification rates do not necessarily reflect the number of recent cases of hepatitis C acquisition in Australia, as many of those who return a positive result do not know when they acquired the infection. Many of those diagnosed at older ages are believed to have been infected when much younger. The incidence rate of newly acquired hepatitis C – that is, those who acquired hepatitis C in the past two years and for which medical evidence is available to support the claim – is greatest among people aged 20-29 years (≈ 6 per 100,000), followed by 30-39 years (≈ 3 per 100,000) and 15-19 olds (≈ 3 per 100,000). Newly acquired hepatitis C, however, represents only a small proportion (less than 4%) of the total number of notifications due to the relatively narrow band of time used in this definition and the need for medical documentation of recent acquisition (NCHECR, 2006a).

The distribution of genotypes in Australia is similar to many other Western countries. Between 50-60% of cases are genotype 1, with a relatively even distribution of subtypes 1, 1a and 1b. A further 30-40% of cases are genotype 3a and a significant minority (10%) are genotype 2 (Crofts, 2001; Dore et al., 2003; Kaba et al., 1998; Mison et al., 1997). A small proportion of infections are genotype 4 and 6 and are believed to be due to migration to Australia from Africa and Asia, respectively, and/or due to Australian citizens travelling to these regions (Crofts, 2001; Kaba et al., 1998). Some variation in those infected with different genotypes is apparent. Genotype 1b is more common among those who contracted hepatitis C through blood transfusions, while genotype 3a is more common among those who contracted the infection through injecting drug use.
(McCaw, Moaven, Locarnini & Bowden, 1997). The average age of those with genotype 3a also tends to be lower than those with genotype 1 (Crofts, 2001).

1.1.5. Correlates of Hepatitis C Infection

Hepatitis C is exclusively transmitted via blood-to-blood contact, unlike other hepatitis viruses in which faecal-oral or bodily fluids are also implicated (AIPC, 2001; Sylvestre, 2003). The relative importance of different correlates of infection in explaining the global spread of hepatitis C varies, in particular, between developed and developing countries. In developed countries, such as Australia, Canada, the United Kingdom and the United States, the primary pathway of transmission is through injecting drug use. In developing countries, on the other hand, blood transfusions and unsafe therapeutic injections represent major correlates of infection for hepatitis C but have largely been eliminated in developed countries. Injecting drug use is also becoming an important factor in developing countries (Crofts, 2001).

Other pathways have been implicated in the transmission of hepatitis C to varying degrees included some non-injecting routes of drug consumption, prison contact, tattooing and skin piercing, vertical transmission, and exposure in the health care setting. Sexual contact and household contact have also been explored but are generally considered not to be associated with the transmission of hepatitis C (Crofts 2001; Crofts, Jolley, Kaldor, van Beek & Wodak, 1997; Dore, Pritchard-Jones, Fisher & Law, 1999; Farrell, Weltman, Dingley & Lin, 1993). The following subsections discuss how each of these risk factors relate to the transmission of hepatitis C and, where evidence is available, how they relate to the Australian and global epidemics.

1.1.5.1. Injecting Drug Use

The single greatest correlate of infection for hepatitis C infection in Australia and many developed countries is injecting drug use and accounts for up to 80% of cases domestically (Dore et al., 1999). The prevalence of hepatitis C among injecting drug
users worldwide is typically very high, with approximately 70% believed to be infected (Hocking, Crofts, Aitken & MacDonald, 2001). The prevalence among injecting drug users in specific countries is variable (Best et al., 1999; Burt et al., 2007; Hagan et al., 2005; Heimer et al., 2002; Hocking et al., 2001; Mathei, Buntinx & van Damme, 2002; Needle, Lambert, Coyle & Havens, 1999; Somaini et al., 2000; Smyth, Keenan & O’Connor, 1998; Vidal-Trecan, Coste, Varescon-Pousson, Christoforov & Boissonnas, 2000; Wada, Greberman, Konuma & Hirai, 2001) but is thought to be higher in countries that have not adopted harm reduction measures, such as needle and syringe programs (Hocking et al., 2001). In Australia, where harm reduction strategies are widespread, the estimated prevalence among injecting drug users is much lower than the global average, with approximately 58% believed to be infected (Hocking et al., 2001). The specific rates reported by studies in Australia have varied considerably and range from as low as 9.5% to as high as 100% (Aitken, Delalande & Staton, 2002; Aitken, Kerger & Crofts, 2002; Crofts & Aitken, 1997; Crofts, Jolley et al., 1997; Crofts, Nigro, Oman, Stevenson & Sherman, 1997; Hellard et al., 2006; Louie, Krousos, Gonzalez & Crofts, 1998; Loxley, Phillips, Carruthers & Bevan, 1997; Loxley et al., 2000; MacDonald et al., 2000; Maher & Sargent, 2002; Maher et al., 2001). Sharing needles or syringes while injecting is believed to be the primary route of transmission among injecting drug users, however sharing injecting-related equipment, such as swabs, water, spoons and tourniquets, has also been implicated (Cheung, Hanson, Maganti, Keeffe & Matsui, 2002; Diaz et al., 2001; Fry, Rumbold & Lintzeris, 1998a; Hagan et al., 2001; Hahn et al., 2002; Kaur et al., 1996; Long et al., 2001; Mathei, et al., 2006; Murrill et al., 2002; Vidal-Trecan et al., 2000; Wada et al., 1999).

The prevalence of hepatitis C among injecting drug users tends to increase with age and duration of injecting career, which also tend to be highly correlated (Dore et al., 1999; Hahn, Page-Shafer, Lum, Ochoa & Moss, 2001; Hellard, Hocking & Crofts, 2004; Hocking et al., 2001; MacDonald et al., 2000; Maher, Chant, Jalaludin & Sargent, 2004; Piccolo et al., 2002; Smyth et al., 1998; Somaini et al., 2000; Thorpe, Ouellet, Levy, Williams & Monterroso, 2000). Injecting drug use typically begins at younger ages and subsequently, those who are still injecting at older ages have typically been doing so for longer periods of time. Within the Australian general population the average age of first
injecting occasion is approximately 22 years (Australian Institute of Health and Welfare [AIHW], 2004) but is much lower among those who are currently injecting illicit drugs. The recent annual report from the *Illicit Drug Reporting System* indicated that the average age of initiation among those who currently inject illicit drugs is approximately 19 years (Stafford et al., 2005), while one survey in Melbourne indicated the average age was 16 years (Crofts, Louie, Rosenthal & Jolley, 1996). The association between age, injecting duration and hepatitis C prevalence is, therefore, likely to reflect the cumulative probability of exposure to the hepatitis C virus. It should be noted however, that those with short histories or durations of injecting still display unacceptably high levels of infection (Garfein et al., 1998; Garfein, Vlahov, Galai, Doherty & Nelson, 1996; MacDonald et al., 2001; NCHECR, 2005; Somaini et al., 2000).

The substance injected is also believed to be associated with hepatitis C infection (Aitken, Delalande et al., 2002). For example, a serological and behavioural survey of 872 people (average age 28.5 years) in Adelaide, Melbourne, Perth and Sydney, Australia, who had injected drugs in the past three months found that injecting opiate-based substances on the last injecting occasion, in addition to duration of use, was an important predictor of infection in both men and women (Carruthers, Loxley, Phillips & Bevan, 1997; Loxley et al., 1997). Similar findings have also been noted in a sample of sex-workers in Miami, United States (Inciardi, Surratt & Kurtz, 2006). There is also some evidence that injecting cocaine may be related to transmission. This is presumed to be due to the high frequency with which users typically inject themselves with this drug, as a result of the short duration of its high (Greenfield, Bigelow & Brooner, 1992; Hocking et al., 2001).

1.1.5.2. **Blood Transfusion**

The possibility of contracting hepatitis C though a blood transfusion is extremely low in Australia (Dore et al., 1999; MacDonald et al., 2001; Wood et al., 2001) and many other developed countries (CLF, 2001; DH, 2004; Moyer et al., 1999; Schüttler et al., 2000) since the introduction of antibody screening of donated blood (in 1990) and donor selection protocol. As a result, notification rates among those who donate blood are
substantially lower than the general population. During the calendar year of 2005, 11 per 100,000 blood donations in Australia were identified as hepatitis C positive (NCHECR, 2006a).

The probability of recipients of blood donation contracting non-A, non-B hepatitis in Australia before screening was introduced was approximately 190 per 100,000 transfusions (MacDonald et al., 2001) but has dramatically decreased to an estimated 1 per 234,000 transfusions (range, 100,000-355,000) in one study (Whyte & Savoia, 1997) or as low as 1 per 400,000-800,000 transfusions in another study (Müller-Breitkreutz, 2000). Similar reductions have been noted in other developed countries (Courouce & Pillonel, 1996; Donahue et al., 1992; Müller-Breitkreutz, 2000; Schreiber, Busch, Kleinman & Korelitz, 1996). Since the introduction of antibody screening and donor selection protocol, hepatitis C infection due to a blood transfusion is thought to be due to receiving blood from an individual who recently acquired hepatitis C and donated blood during the window period (Whyte & Savoia, 1997).

Individuals with medical conditions that require frequent blood transfusions, such as those with haemophilia, have much higher rates of hepatitis C (Farrell et al., 1993; Wood et al., 2001). Historically, those who contracted hepatitis C through a blood transfusion have accounted for 5-8% of the overall hepatitis C positive population. However, this proportion will decline over time as the incidence of new cases has become extremely low (Wood et al., 2001).

1.1.5.3. Therapeutic Injections

The role of therapeutic injections, such as immunisation, disease treatment and vitamin supplements, is very important in understanding the spread of hepatitis C worldwide. It is partially important in developing countries, although has largely disappeared as a mode of transmission in developed countries since the introduction of disposable needles and syringes (Crofts, 2001; Simonsen, Kane, Llyod, Zaffran & Kane 1999; Kane, Llyod, Zaffran, Simonsen & Kane, 1999). Estimates by the WHO suggest that approximately 8-12 billion therapeutic injections occur in developing countries each
year. A large proportion (70-99%) of these injections are considered unnecessary, that is, they were performed when oral treatment was available, when the treatment did not concord with the condition or when the injection was inappropriate or harmful. Individuals in developing countries receive an average 1.5 injections per year however, child and institutionalised adults receive 10-100 times as many injections (Simonsen et al., 1999). Moreover, and more importantly, up to 50% of injections performed in developing countries are with a reused needle and/or syringe that had not been sterilised (Kane et al., 1999).

Unsafe therapeutic injections, coupled with large numbers of unnecessary injections, result in an estimated 2.3-4.7 million new hepatitis C infections in developing countries annually (Kane et al., 1999). One of the most frequently cited examples of the systematic transmission of hepatitis C and other blood-borne viruses due to therapeutic injections was in Egypt during the 1920’s to 1980’s. Much of the population were treated for schistosomal, a trematode worm also known as blood fluke (MedlinePlus, 2006), and resulted in the highest population prevalence of hepatitis C worldwide (Crofts, 2001; Frank et al., 2000; Simonsen et al., 1999).

1.1.5.4. Non-injecting Drug Use

There is some evidence suggesting that non-injecting routes of drug consumption, such as snorting cocaine, may increase the likelihood of contracting hepatitis C (Hahn et al., 2001). Koblin, Factor, Wu and Vlahov (2003), in a study of 276 non-injecting drug users aged between 15 and 40 years in New York City, United States, found that 4.7% were hepatitis C antibody positive. The only behavioural factor they found to be significantly related to serostatus was having ever snorted or sniffed heroin in combination with cocaine. It is suggested that transmission of the hepatitis C virus may occur in these circumstances as a result of bleeding from the nose due to the inhalation of these substances and sharing “straws” or other snorting equipment (Koblin et al., 2003; MacDonald et al., 2001).
1.1.5.5. Prison Contact

Several studies have indicated that contact with a prison system is associated with higher rates of hepatitis C. This finding stems from two streams of research. First, studies from a number of jurisdictions from across the world, including Australia, have noted high rates of hepatitis C among people who enter prison or juvenile detention centres (Feldman, Sorvillo, Cole, Lawrence & Mares, 2004; Long et al., 2001; Malliori et al., 1998; Ogilvie, Veit, Crofts & Thompson, 1999). Second, studies with non-prison based samples have noted that having ever spent time in prison is a significant predictor of infection (Aitken, Delalande et al., 2002; Cook, McVeigh, Syed, Mutton & Bellis, 2001; Kittikraisak et al., 2006; Ogilivie et al., 1999; Maher et al., 2004).

The high prevalence noted in these studies is believed to be primarily due to the sharing of needles and syringes to inject illicit drugs while incarcerated. These practices are often caused by the hurried nature of injecting in prison, due to the prohibited nature of drug use and the higher level of surveillance prisoners experience than the general community. Moreover, prisoners tend to engage in unsafe practices while injecting because of the inaccessibility of new or clean needles or syringes in prison, as only a very small number of prison systems around the world provide such access (Crofts & Wodak, 2001; MacDonald et al., 2001).

Tattooing while in prison had also been implicated in the transmission of hepatitis C, again primarily through engaging in non-sterile practices due to the inaccessibility of clean equipment (MacDonald et al., 2001). Hellard and colleagues, for example, in a study of 642 prisoners in Victorian correctional facilities, found that over one-quarter (28%) had been tattooed while in an adult or juvenile prison. Moreover, they found that being tattooed while in prison was a significant predictor of hepatitis C infection among those with a history of injecting drug use but also among those who had never injected illicit drugs (Hellard, Aitken & Hocking, 2007; Hellard et al., 2004).

The high prevalence of hepatitis C attributed to contact with a prison system may also be due to the personal histories of those entering prison, with a large number of
prisoners experiencing drug dependency issues, particularly in relation to injectable substances (Crofts & Wodak, 2001; Feldman et al., 2004; Long et al., 2001).

1.1.5.6. Tattooing and Skin Piercing

Tattooing and skin piercing have been implicated as practices likely to transmit hepatitis C from one person to another (Garner, Gaughwin, Dodding & Willson, 1997; Hepatitis C Council of Victoria, 2003; MacDonald et al., 2001; Roy, Haley, Leclerc, Boivin, Cedras & Vincelette, 2001). In Australia, tattooing and skin piercing are relatively common practices among the general community and many are not performed by a professional on a registered premises in accordance to health and safety standards (e.g. Department of Human Services [DHS], 2004). A telephone survey of 757 Victorian residents revealed that approximately 5% had at least one tattoo, while 50% had at least one skin piercing. The majority of those with a tattoo or skin piercing reported that the procedure had been performed by a professional, however one-quarter (24%) of those with tattoos and 15% of those with piercings reported that the procedure had been performed by a non-professional (Watson et al., 1999). Much higher rates of tattooing and skin piercing have been noted among a sample of university students from multiple sites across the United States (Greif, Hewitt & Armstrong, 1999).

Adding to the concern about the potential transmission of hepatitis C via skin piercing practices are the findings of a small number of Australian studies. These studies indicate that levels of hepatitis C knowledge and adherence to local tattooing and skin/ear piercing guidelines among licensed piercing practitioners is highly variable. This is despite the majority of establishments reporting they possess and have read relevant guidelines (Hellard, 2002; Hellard et al., 2002; Hellard, Aitken, Mackintosh, Ridge & Bowden, 2003; Oberdorfer & Wiggers, 2002). In a study of 35 piercing establishments and their owners across Victoria, for example, Hellard et al. (2002) found that all practitioners reported using single use needles to perform some piercing procedures and disposing of them correctly in a sharps container. However, 14 of the 20 practitioners who used piercing guns did not clean them according to guidelines, while 7 of the 29 practitioners who used clamps and tongs during piercing procedures did not clean them.
according to guidelines. They also found that knowledge of hepatitis C and adherence to guidelines among those who performed piercing as a secondary activity (e.g. hairdressers, beauticians, or chemists) tended to be much lower than those who performed piercing as a primary activity (e.g. piercers or tattooists).

The prevalence of hepatitis C infection as a result of tattooing or skin piercing has not been well documented. However a small number of studies have reported either a weak or no association (Alter et al., 1997; Garner et al., 1997; Roy et al., 2001).

1.1.5.7. Vertical Transmission

Vertical transmission refers to the transmission of hepatitis C, or other infections, from mother to child during pregnancy. While the mechanisms through which this occur for hepatitis C are not well understood (MacDonald et al., 2001), it is suggested that all children born to mothers who are hepatitis C ribonucleic acid (RNA) positive will test antibody positive immediately after birth. A small percentage of these infants – generally held to be between 5-10% – will remain positive 12-18 months after birth. The percentage has varied considerably between studies and has ranged from 0% to 42% (Dore, Kaldor & McCaughan, 1997; Giles, Hellard & Sasadeusz, 2003; Granovsky et al., 1998; MacDonald et al., 2001; Resti et al., 1998). There have been no recorded instances of neonates testing positive to hepatitis C antibodies whose mothers who were hepatitis C RNA negative (Granovsky et al., 1998).

Factors associated with vertical transmission are also poorly understood. The most consistent findings suggest the presence of maternal viremia, high viral load, or HIV coinfection increase the likelihood of transmission. Other factors, such as mode of delivery, gender of the child, patterns of breastfeeding, and maternal behavioural and personal factors, such as age, ethnicity and drug use, have yielded inconclusive or mixed results in predicting mother to child transmission (Granovsky et al., 1998; MacDonald et al., 2001; Resti et al., 1998).
1.1.5.8. Health Care Setting

Hepatitis C is infrequently transmitted in the health care setting. The primary source of transmission is from patient-to-practitioner through needle stick injury. The probability of transmission from such an injury is estimated to be 2-8% (AIPC, 2001; Dore et al., 1999; Dore et al., 1997; Farrell et al., 1993; MacDonald, 2001). Cooksley and Butterworth (1996), in a study of 33 health care workers in Australia who had been referred for management after receiving a positive hepatitis C antibody test, found that the mode of transmission for health care workers largely reflected that of the broader population. Only two workers had documented evidence of needle stick injuries coupled with seroconversion at an approximately plausible interval after the injury had occurred. Although extremely unlikely, patient-to-practitioner transmission may also occur through blood spills. There have also been only a very small number of documented cases globally in which transmission has occurred from doctor to patient during surgery (MacDonald et al., 2001).

1.1.5.9. Sexual Contact

Sexual contact as a mode of transmission for hepatitis C is a contentious issue. Traces of hepatitis C virus RNA have been found in semen and vaginal fluids indicating that transmission through sexual contact is theoretically plausible. It is however, typically considered to play a very small role, if at all (Dore et al., 1999; Hammer et al., 2003; MacDonald & Wodak, 1999; Rosenblum, Nuttbrock, McQuistion, Magura & Joseph, 2001; Thorpe et al., 2000). The association between sexual contact and hepatitis C infection appears, in part, to be driven by research undertaken in the United States, where between one-fifth and one-quarter of infections are attributed to sexual contact (Crofts, 2001; MacDonald et al, 2001). The social, cultural and political environment in the United States in relation to drug use and injecting practices calls into question the validity of these findings. In the United States the revelation of drug use and injecting drug use may have significant repercussions for individuals in terms of the possibility of employment, the receipt of health insurance, or the possibility of imprisonment. This
environment is likely to leave those recently diagnosed with hepatitis C reluctant to reveal to clinicians or official bodies their involvement in injecting drug use (Crofts, 2001).

The link between sexual contact and hepatitis C transmission has also arisen from an observation that people who typically have multiple sexual partners, such as sex workers and men who have sex with men, have higher rates of hepatitis C than the broader population. The rates of hepatitis C infection in these populations, however, are considerably lower than infections for which sexual contact has been confirmed to have a significant role in transmission, such as HIV, hepatitis B and other sexually transmitted infections (STI) (Crofts, 2001; Hammer et al., 2003; MacDonald et al., 2001). Further evidence discrediting the role of sexual contact comes from research conducted with long-term partners of people with chronic hepatitis C. These studies indicate a low prevalence among partners, typically equal to or lower than the general population (Crofts, 2001; Kao et al., 2000; Marincovich et al., 2003; Tahan et al., 2005; Terrault et al., 2003; Vandelli et al., 2004), and suggest the apparent clustering of hepatitis C infection within sexual couples is attributable to shared injecting practices (McMahon, Pouget, Tortu, 2007; Stroffolini, Lorenzoni, Menniti-Ippolito, Infantolino & Chiaramonte, 2001).

1.1.5.10. Household Contact

There is little or no evidence to suggest that household contact, such as sharing household utensils or living space, increases the likelihood of contracting hepatitis C (AIPC, 2001; Dore, 2001; MacDonald et al., 2001). There is a small likelihood of transmission through sharing toothbrushes or razor blades, given the possibility these items may carry blood. Some studies have found evidence of clusters of infection in families, however these studies have generally been undertaken in countries, such as Egypt, where the population or background prevalence is very high (MacDonald et al., 2001).
1.2. Hepatitis C Testing

1.2.1. Overview

An issue that has largely been ignored in hepatitis C research are the human factors associated with testing (Loxley et al., 2000), such as who is tested for hepatitis C, why they are tested, and what their experiences are of being tested. An understanding of these issues is vital for the development of strategies aiming to prevent the spread of hepatitis C, as many of those with hepatitis C are not aware of their serostatus and may spread the infection without their knowledge (Australian National Council on AIDS and Related Diseases [ANCARD], 2002; Centers for Disease Control and Prevention [CDC], 1998). Understanding these issues can also lead to the development of more tailored approaches to testing and more positive experiences and outcomes for testing recipients and for broader public health concerns, such as the prevention of hepatitis C in the community (Loxley et al., 2000).

The precise proportion of those infected with hepatitis C who are unaware of their serostatus is difficult to determine. Although little evidence is presented to support these figures, up to 40% of those infected with hepatitis C in Australia are unaware they are positive (Dore et al., 1999), while in the United States this figure is approximately 50% (Gordon, 1999; Rhodes, DiClemente, Yee & Hergenrather, 2001). A crude means of estimating this figure is to calculate the total number of notifications as proportion of the estimated population of hepatitis C positive individuals. In Australia there have been 225,000 notifications for hepatitis C recorded through the National Surveillance System to the end of 2005 (NCHECR, 2006b). A simple calculation suggests that approximately 15% of the estimated 264,000 people who have been exposed to the hepatitis C virus are unaware of their serostatus. The number of notifications however, does not account for repeated testing of the same individual and, as such, the actual proportion of those unaware of their status is likely to be much higher.

A second means of estimating the proportion of those unaware of their serostatus is from the small number of studies that have directly examined the concordance between self-reported status and serological status. These studies indicate that concordance tends
to be very high among adult injecting drug users and prisoners who believe they are hepatitis C positive, with between 93% and 100% accurately reporting their status. The accuracy of self-reported status for those who believe they are hepatitis C negative is considerably more variable, with between 33% and 88% correctly knowing their status (Best et al., 1999; Cook, McVeigh, Syed, Mutton & Bellis, 2001; Hagan et al., 2005; Schlichting et al., 2003; Somaini et al., 2000; Stein, Maksad & Clarke, 2001; Thornton et al., 2000). Estimates among the general population have not been undertaken.

1.2.2. Hepatitis C Testing Literature Search

A comprehensive literature search was undertaken to review previous research on hepatitis C testing. The results of this search form the basis for the remainder of this chapter. Many other literature searches were conducted for this thesis however, only the search relating to hepatitis C testing is described in detail here, as it is the central topic of this thesis. This search was performed using three literature databases: 1) Cambridge Scientific Abstracts, which included PsycINFO, Sociological Abstracts and Social Services Abstracts, 2) Web of Science, and 3) Current Contents Connect. The search was limited to the years 1985 to 2005 (the year in which the search was performed), although the search was performed through an automated electronic system on a weekly basis to identify new publications. The keywords “hepatitis”, “HCV” and “blood borne virus” were used to build a pool of literature to further interrogate. The keywords “test*”, “screen*” or “counselling” were then used to identify relevant publications. The search was not limited by publication type or language, although in the case of the latter only English language publications were retrieved. Although the primary focus of this thesis is to examine hepatitis C testing within the context of an Australian urban environment, namely Melbourne, the search was not limited to Australian publications. Studies undertaken in other countries, particularly from developed regions, were included even though the service provision, policy and political environments may differ substantially to Australia, because they can still provide valuable insights into the

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2 The asterisk was used to search for all words related to the root word (e.g. testing, tested, testee) and is a common feature of literature databases.
nature of testing given the similarity in patterns of risk factors for hepatitis C. A search of the publication lists of a number of Australian research organisations specialising in drug use and blood borne viruses was also undertaken to locate research findings that had not been published in peer reviewed journals or commercially available books. Using this search strategy fewer than 20 research articles and institutional reports were identified.

The majority of publications identified through these searches did not specifically examine testing, but instead, reported the prevalence of testing within the context of a larger study examining hepatitis C risk factors, knowledge of risk factors and/or the effectiveness of prevention or intervention programs. The reported prevalence rates relate to either testing that occurred prior to recruitment or testing uptake as part of a service-delivery model or research program. Two institutional reports detailed the number of hepatitis C tests undertaken in Australia annually. Only a small number of these studies examined testing in greater detail albeit to varying degrees; six studies reported the correlates of hepatitis C testing, while two studies reported the reasons for hepatitis C testing.

Approximately one-third of the publications on hepatitis C testing were undertaken with samples located in Australia and the United States. The remaining third were undertaken in countries located within the European Union, such as England, France, Ireland and Switzerland. The majority of the research literature focused on populations defined by the practices in which they engage and are designated to be at risk for infection. These where predominately injecting drug users and people attending drug treatment centres. Only four studies report findings with other cohorts, although all are viewed as groups that are more likely to engage in unsafe practices. Two studies, one in Australia (Van de Ven, Kippax, Crawford & Rodden, 1999) and one in the United States (Rhodes et al., 2001), recruited men who have sex with men; one study in the United States recruited veterans with HIV (Fultz et al., 2005) and another in the United States recruited people with serious mental illness (Goldberg et al., 2005). The majority of participants in all of these studies were adults, although approximately one-quarter included a small number of participants under the age of 18. Only two studies
specifically examined young people; one study recruited 15 to 25-year-olds in Australia (Myers et al., 2005), while the other recruited 15 to 22-year-olds in the United States (Lifson & Halcón, 2001).

The lack of research on the human aspects of hepatitis C testing may, in part, be due to the relatively recent emergence of and focus on hepatitis C. The field is little more than 15 years old and the initial focus, as is the case for many newly identified infections or diseases, has been to determine the size of the problem and the factors that lead to individuals acquiring the problem. In recent times, there has been increasing focus on treatment and preventive strategies. Alternatively and unfortunately, the establishment of broadly accepted testing policies in Australia (e.g. ANCAHRD, 2003) and other developed countries (e.g. DH, 1996, 2004; CDC, 2001a, 2001b) may have led to a perception that the issue of testing is resolved and, therefore, redundant or not worthy of further investigation.

1.2.2. Number of Hepatitis C Tests

A large number of hepatitis C tests are conducted in Australia each year and has been steadily increasing over the past decade (ANCAHRD, 2003). The specific number of tests that are conducted is difficult to determine, given the manner in which data are collected through government agencies and departments responsible for the monitoring and payment of serological testing. The National Serology Reference Laboratory (2004), which is responsible for maintaining the quality of serological testing in Australia, reports that in 2004 approximately 1.9 million hepatitis C antibody tests were recorded through their program. This total includes testing that was performed as part of the national blood collection service and those conducted as regular diagnostic testing. The number of tests conducted in 2004 represents a slight increase from 2003 and is only slightly less than the total number of HIV tests recorded. These figures may underestimate the total number of tests performed, as not all laboratories participate in the quality assurance program. The population of Australia in 2004 was estimated to be 20.1 million people (Australian Bureau of Statistics [ABS], 2006), which provides a crude rate for hepatitis C testing of 95 per 1,000. This rate is likely to overestimate the
rate of testing, given that individuals may be tested several times during the course of a year.

A second source of data from which to estimate the number of hepatitis C tests conducted in Australia is Medicare statistics. The number of hepatitis C tests charged to Medicare is also difficult to determine, as antibody testing is coded under seven item numbers within the Medicare schedule; three relate to antibody testing for general diagnostic testing purposes and four relate to screening specifically during pregnancy. A further complication to the interpretation of these data is that the item numbers do not solely relate to hepatitis C. In the case of testing for general diagnostic purposes, the items also include testing for hepatitis A, hepatitis B and hepatitis D (the latter only when the individual has previously tested positive for hepatitis B). In the case of screening during pregnancy, rubella, syphilis and hepatitis B are also included. The items within these two groupings (general testing and pregnancy screening) are sequentially related and indicate the number of tests that were conducted within the grouping. For example, in the case of the four items relating to pregnancy screening, they indicate whether one, two, three or four of the infections from the list were included in the screening. Such issues notwithstanding, these data indicate that for the financial year of 2004-2005, between 238,195 and 967,093 hepatitis C antibody tests were conducted and charged to the Medicare system. This total is comprised of 141,107-768,153 tests for general diagnostic testing and 97,088-198,940 for screening during pregnancy (Medicare Australia, 2006a).

1.2.3. Prevalence of Testing

The population prevalence of hepatitis C testing has been estimated in only one study in Australia. Watson et al. (1999) conducted a telephone survey of 757 people living in

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3 Medicare is the federally funded universal health care system available to all Australian residents. It covers the costs associated with being a patient in public hospitals and a scheduled amount of the fee for medical practitioners (e.g. general practitioner and specialists) and medical services (e.g. serology service and medical imaging) outside of public hospitals (Medicare 2006b)
4 Medicare item numbers: 69475, 69478 and 69481
5 Medicare item numbers: 69405, 69408, 69411 and 69413
Victoria and estimated that 10.9% of the state’s population have ever been tested for hepatitis C. There have been no population studies reported in the international literature.

The prevalence of testing within unrepresentative samples of specific populations is more commonly reported and is typically much higher than in the general community. Studies with people who inject drugs or are in drug treatment programs in Australia show that 38-70% had been tested on at least one occasion (Aitken, Kerger et al., 2002; Myers et al., 2005; Loxley et al., 2000). Studies of similar populations in other countries also indicate a very high prevalence of testing. The rate of lifetime testing in one study of opiate users in treatment in England was reported as 87% (Best et al., 1999), while among a sample of injecting drug users attending methadone treatment in Ireland another study found that 80% had been previously tested (Smyth et al., 1999). Vidal-Trecan et al. (2000), in a study of French injecting drug users, report that 63% had consistently sought hepatitis C testing, although a definition of consistent testing was not provided, while Burt et al. (2007), in the secondary data analysis of four large studies of injecting drug users aged 18-30 in the Seattle-area (United States), report that 73% had ever been tested for hepatitis C.

The prevalence of testing among other populations deemed at-risk but not defined by drug use practices is typically lower than among injecting drug users. The only other study in Australia to report the prevalence of testing was with a sample of men who have sex with men among whom 41% had previously been tested (Van de Van et al., 1999). Non-injecting at-risk populations are the primary cohorts among which hepatitis C testing prevalence is reported in research from the United States. Among a sample of men who have sex with men the lifetime prevalence (39%) was very similar to the Australian study described above (Rhodes et al., 2001). Goldberg et al. (2005) report that 41% of a sample of people with serious mental illness had been previously tested, while Fultz et al. (2003) report the lifetime prevalence of testing among a cohort of HIV positive veterans was 80%. The only study to report the prevalence of hepatitis C testing among a group of exclusively homeless young people (aged 15-22 years) was also
undertaken in the United States and found that 25% had been previously tested (Lifson & Halcón, 2001).

1.2.4. Location of Testing

The setting in which hepatitis C testing occurs is as diverse as the services and programs which provide health care. In a study of 362 women living with hepatitis C in Victoria, Australia, O’Brien, Gifford, Banwell and Bammer (2001) found that a little over half of the women had received their diagnosis from their regular general practitioner and that approximately one-tenth had received it from a general practitioner with whom they had not visited before. They also found that 13% of the women who were currently injecting drugs had received their diagnosis at a drug or alcohol service, while 4% had done so while in jail or detention. Of those who had injected in the past (but not currently) or had never injected, 9% had received their diagnosis from the national blood donation service.

A slightly different story to the location of testing was reported in a survey of 105 young people aged 15-25 years (half of whom were currently homeless) contacted through a pilot outreach program in Melbourne, Australia. The findings from this survey indicated that slightly under one-third of young people had last been tested at their regular general practitioner clinic. A further one-third had last been tested at a drug and alcohol clinic, 15% while in prison or detention, and 13% at another unspecified location (Myers et al., 2005). The location of testing has not been reported in international literature.

1.2.5. Who is Tested for Hepatitis C?

Only six of the studies reporting the prevalence of hepatitis C testing also examine the correlates or predictors of testing. The most consistent findings to emerge from these studies, regardless of the country in which it was undertaken, were that those who engaged in so-called risk practices, in particular injecting drug use; those with better
knowledge of hepatitis C; and those who have contact with health services for other blood-borne viruses, are more likely to have been tested for hepatitis C.

Three of the six studies that examine the correlates of hepatitis C testing were undertaken in Australia. Watson et al. (1999), for example, in their survey of hepatitis C risk factors among Victorian residents, found that after controlling for all other factors, those who had also been tested for hepatitis B, had previously injected drugs, had previously donated blood, and women were significantly more likely to have ever been tested. Those who been vaccinated for hepatitis B, on the other hand, were less likely to have been tested. The association between testing, hepatitis C knowledge and injecting drug use was also found among participants in a telephone survey of Australian men who have sex with men (Van de Ven et al., 1999), while Myers et al. (2005) found that young people aged 20-25 years were much more likely to have been tested than those aged 15-19 years. Other factors were unfortunately not examined in the latter study.

The remaining three studies that have examined the correlates of hepatitis C testing were all undertaken in the United States. Rhodes et al. (2001) in a survey of 381 men who have sex with men aged 18-78 years (average 38 years) recruited via the Internet, found that having ever been tested for hepatitis C was associated with a large number of factors including sexual orientation, HIV status, hepatitis B vaccination, greater hepatitis C knowledge, as well as specific sources of this knowledge, the number of lifetime sexual partners, engaging in tattooing or skin piercing, ever sharing needles to inject drugs, and ever using a straw or similar device to snort cocaine. However, when these variables were entered into a multivariate model, only history of tattooing and skin piercing, increased knowledge of hepatitis C and greater communication about hepatitis C with a health care provider remained statistically significant. Injecting drug use was the only significant predictor of testing uptake, among the six variables examined, in a study of drug users in treatment. The five variables found not to be related to testing were age, gender, needle sharing, being on a maintenance schedule, or the type of maintenance (Serfaty et al., 1997). Among a sample of 200 adults with psychotic or mood disorders in the United States, no behavioural factors were associated with hepatitis C testing. The only factor that was associated was the presence of a comorbid
medical condition (Goldberg et al., 2005). Due to the paucity of research on this issue, it is difficult to determine whether the results of these studies are representative of the populations studied or if they can be generalised to other populations.

Typically, hepatitis C testing is not undertaken in isolation. Although they did not examine other correlates of testing, Loxley et al. (2000) report that the majority of the injecting drug users they interviewed indicated they had been tested for hepatitis C as part of a battery of tests for blood-borne viruses, which also included hepatitis B and/or HIV. Moreover, the majority thought of the battery of tests as a single test rather than as a collection of individual tests. This finding is consistent with the practices of many services and agencies that provide blood-borne virus testing as all or part of their mandate. Victorian services based in Melbourne, such as the Melbourne Sexual Health Centre, Healthworks, Turning Point Drug and Alcohol Centre, Family Planning Victoria and many others, routinely assess risk practices among their clients and offer appropriate testing.

1.2.6. Why are People Tested for Hepatitis C?

Only two studies report the reasons why people undertake hepatitis C testing. These studies were undertaken exclusively in Australia and recruited people who currently injected illicit drugs. Both studies used limited qualitative methods, namely open-ended survey questions delivered in an interview format, and found that injecting drug users often sought or accepted testing after engaging in a practice they perceived to be risky or of concern, because of opportunity or requirement, or out of concern for other people in their life (Aitken, Kerger et al., 2002; Loxley et al., 2000).

Within the context of a pilot peer-delivered hepatitis C testing and counselling program in Melbourne, Australia, Aitken, Kerger et al. (2002) examined hepatitis C testing uptake among 47, mainly adult, injecting drug users who had not been tested in the past

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6 This information was gleaned from conversations I had with many health care workers from services across Melbourne over the course of my candidature.
12-months. Participants were offered free hepatitis C testing and, upon agreeing, asked why they wanted to be tested. The reasons provided by participants showed that they had been tested in an environment in which they felt comfortable and were grouped into four broad, not mutually exclusive, categories. Over two-thirds of participants stated they had accepted testing because of the convenience and ease of testing in the pilot program. A further one-quarter felt comfortable being tested in a familiar environment, while one-fifth had been tested because they were uncomfortable about disclosing their drug use status to their regular doctor or expected poor treatment in a clinical setting. A similar proportion felt motivated by recent risky practices. Although these findings were not interpreted, it suggests that uptake of testing, at least for these injecting drug users, was opportunistic rather than as a result of concerted deliberation.

Loxley et al. (2000), as part of a larger study of injecting drug users, examined the reasons for past blood-borne virus testing and found a slightly different pattern of reasons than Aitken and colleagues did for testing uptake. They interviewed 200 predominately heroin and amphetamines users aged 14-27 years (31% were 20 years or younger) in Perth, Australia, and asked them separate questions regarding hepatitis B, hepatitis C and HIV testing. Although little evidence is presented, they report the reasons for testing were similar for all blood-borne viruses. The only major difference found was regarding hepatitis B testing, which related to having experienced signs or symptoms. They found that generally the reasons for blood-borne virus testing could be grouped into three broad categories. First, half of the participants had previously sought testing in response to exposure. The main behaviours mentioned by participants were unsafe injecting practices, unsafe sexual practices, and associating with others who either had a blood-borne virus or engaged in practices that increased the likelihood of contracting a blood-borne virus. The practices were sometimes a one-off or occasional recent act, practices that had occurred some time in the past, or were regular practices. Secondly, approximately one-quarter reported that testing was due to the recommendation or requirement of others, for example a doctor or health practitioner, when receiving drug treatment or while in prison. A high degree of coercion was often reported in these testing episodes. The third broad reason, reported by approximately one-fifth of participants, was concern about the possibility of passing it on to others.
The concern was often in connection to an intimate relationship or intention to have children in future.

1.2.7. HIV Testing Research

Testing has received a much greater research focus within the HIV/AIDS field. As with the hepatitis C testing literature, this research has focused on populations defined by the practices in which they engage and are deemed at-risk or high-risk. These populations include men who have sex with men, injecting drug users and homeless young people. This stream of research has also focused on the issues of who is tested and why they are tested. This literature is relevant to hepatitis C testing because of the similar role injecting drug use can have in the transmission of these viruses.

1.2.7.1. Who is Tested for HIV?

Studies examining the correlates of HIV testing have almost exclusively been undertaken in the United States and indicate that those who engage in practices associated with the transmission of HIV are more likely to have been tested, and tested more often, than those who do not engage in such practices (Anderson, Carey & Taveras, 2000; CDC, 2004a, 2004b; de Rosa, Montgomery, Hyde, Iverson & Kipke, 2001; Fernyak, Page-Shafer, Kellogg, McFarland & Katz, 2002; Grella, Campos & Anglin, 1998; Maguen, Armistead & Kalichman, 2000; Zwahlen, Neuenschwander, Jeannin, Dubois-Arber & Vlahov, 2000). The specific practices found to be associated with testing tend to cluster around sexual practices, such as unprotected sex, recent sexual contact and multiple sexual partners (Pugatch et al., 2001; Maguen et al., 2000; Van de Ven, Kippax, Crawford & French, 1997), and drug-related practices, such as injecting drugs, infrequent needle cleaning, frequent needle sharing and speed or amphetamines use (Grella et al., 1998; Burchell et al., 2003). People who believe they are susceptible or possess high self-perceived risk of HIV, have contact with people who are HIV positive, or have had a STI are also more likely to have been tested (Dore et al., 1999; Grella et al., 1998; Strauss, Deren, Rindskopf & Falkin, 2002; Maguen et
al., 2000; Burchell et al., 2003; Pugatch et al., 2001). Age, sex and sexual identity have found to be associated with HIV testing, although these factors have not been consistently reported or reported to have a consistent effect (Strauss et al., 2002; Zwahlen et al., 2000; Pugatch et al., 2001).

Despite relatively consistent findings that those deemed at greater risk for HIV are more likely to be tested for HIV, significant numbers of individuals with no identifiable risk factors are still being tested for HIV in many countries, including Australia (Lupton, McCarthy & Chapman, 1995; Thompson, Stevenson & Crofts, 1996) and the United States (Anderson, 2004; Anderson, Santelli & Mugalla, 2003; Fernyak et al., 2002). A population-based study of sexually active adults (aged 18-50 years) conducted across four US states (Florida, Montana, Ohio, and South Dakota), for example, found that those who reported one or more HIV risk factors were substantially more likely than those who did not report a risk factor to have been tested for HIV in the past 12 months (49% vs. 35%, respectively). HIV risk, in this study, was broadly defined as having sex with two or more people with or without a condom, injecting illicit drugs, being diagnosed with an STI (not HIV) or having anal sex without a condom in the past 12-months, or ever being diagnosed with HIV. However, given that slightly less than 20% of the population was deemed at risk, according to these criteria, the rate of testing among those at low or no risk actually represented the vast majority of those who are received HIV testing (Takahashi et al., 2005).

Absent from the hepatitis C testing literature but present within the HIV testing literature are studies focusing on young people who experience homelessness. These studies, all undertaken in California, United States, are consistent with research with other so-called at-risk or high-risk groups and conclude that those who engage in practices likely to transmit the virus are more likely to be tested. Goodman and Berecochea (1994), for example, indicate that HIV testing, among a sample of 13 to 18-year-old young people who experience homelessness, was independently related to having ever had a STI, more than four years since commencing sexual relationships, injecting drug use and older age. Rotheram-Borus, Gillis, Reid, Fernandez and Gwadz (1997) found that self-identified gay, lesbian and bisexual young people and injecting
drug users were more likely to be tested. De Rosa et al. (2001) found that the length of
time young people had been homeless correlated with previous testing, with those who
had been homeless for more than one year being more likely to have been tested than
those who had been homeless for less than one year. They also found that those who
were older, talked about HIV with their friends or an outreach worker, knew someone
who was HIV positive, were sexually active, engaged in survival sex (i.e. having or
trading sex to meet subsistence needs), had ever tested for an STI, or ever injected drugs
were more likely to be tested. A surprising finding, and one that was inconsistent with
studies of HIV testing among adults (e.g. Pugatch et al., 2001; Maguen et al., 2000),
was that those with a lower perceived risk were also more likely to have sought testing.
The authors speculate this finding may indicate that young people make assessments of
their likelihood of contracting HIV based upon the outcome of the test, rather than on
engaging in specific practices. Young people felt they were less likely to contract HIV
because the result of their test indicated they were infection free.

1.2.7.2. Why are People Tested for HIV?

Many of the reasons cited for hepatitis C testing are mirrored in the HIV literature.
From this body of literature, the bulk of which was undertaken in the United States, the
most frequently reported reasons for testing include allaying concern about past or
current practices, or concern for significant others’ safety due to engagement in unsafe
practices (Burchell et al., 2003; Chippendale, French & Miller, 1998; Exner, Hoffman,
Parikh, Leu & Ehrhardt, 2002; Grella et al., 1998; Kellerman et al., 2002; Murphy,
Mitchell, Vermund & Futterman, 2002; Patinkin et al., 2007; Ransom, Siler, Peters &
Maurer, 2005; Riess, Kim & Downing, 2001; Van de Ven et al., 1997). Also consistent
with the small amount of research on hepatitis C is the finding that some people are
tested because of a requirement by an institution, such as a prison or hospital, or feel
they are coerced into having a test by health care workers (Grella et al., 1998; Murphy
et al., 2002; Riess et al., 2001; Tobin, Tang, Gilbert & Latkin, 2004).

In a study of 14 injecting drug users (aged 16-36 years) in the United Kingdom, Hughes
(2002) used in-depth interviews and vignettes to examine perceptions of HIV risk in and
out of prison. From participant’s recounting of their own personal experiences and responses to vignettes, two themes relating to reasons for HIV testing were described. First, many of those interviewed had sought, and saw it necessary to seek, testing to determine whether transmission had occurred after engaging in unsafe sexual or injecting-related practices. Some participants suggested it was important to immediately seek testing after engaging in unsafe practices, however, many did not express an understanding of the uncertainty of a negative result so soon after exposure. Testing was also more likely to be seen as necessary after sharing injecting equipment with someone they did not know, compared with sharing with close friends or sexual partners. Although not interpreted, this difference may suggest that emotional closeness or intimacy may alter perceptions of the danger and safety of injecting practices. Hughes also found there was less of an emphasis on the need for testing following engagement in unsafe sexual practices, which he suggests may reflect a belief that injecting drug use is a greater danger than sexual practices in the transmission of HIV. The second theme to emerge from Hughes’ research was that some injecting drug users had sought testing out of concern for, or urging from, other people. Testing under these circumstances was typically within the context of a sexual relationship and seen as a demonstration of cleanliness and closeness to the other person and borne of a desire to do them no harm. For some participants, testing was associated with discontinuing condom use.

A clue to the apparent disparity between sexual and drug-related practices evident in Hughes’ study can be drawn from the work of Hillier, Dempsey and Harrison (1999). They interviewed young people who had experienced homelessness in Victoria and Queensland, Australia, about their drug use and sexual practices. They identified that young people who engaged in injecting drug use had a strong belief in the idea of safe injecting practices. This belief was characterised by the distinction between “druggies” and “junkies”. Druggies, they stated, engaged in safe injecting practices in contrast to junkies. All of the young people interviewed saw themselves as druggies; they were responsible drug users who did not share injecting equipment and endeavoured to make sure others also did not. The category druggies also served to separate themselves and their engagement in illicit drug use from the stigmatised view of such practices typically held by mainstream society. Junkies, on the other hand, was a term used to describe
those whose drug use was identified as dirty and destructive. Junkies were viewed as immoral and reckless individuals who posed a danger to others. Young people’s discussion of sexual practices however, did not reveal a clear or consistent picture of safe sexual practice, as was evident for injecting practices. Moreover, many young people spoke about their ambivalence towards engaging in safe sex practices. This ambivalence was particularly evident in sexual relationships where using condoms was often held as contradictory to the development or demonstration of trust in their relationship.

A striking difference to the hepatitis C literature is reported in one of the few studies not exclusively examining so-called high-risk groups. Lupton and colleagues (1995) interviewed 41 heterosexual and bisexual adults of varying ages in Australia. Their findings suggest that some people seek HIV testing for reasons other than because they feel at high-risk. For some people the outcome of the test was less important than the ritual of having the test. They report that some people had been tested in the past because of pressure from parents or partners, the desire to give up the use of condoms in sexual relationships, commencement of a new or end of an old sexual relationship, and ideas about responsibility. People’s stories, particularly those in sexual relationships, also revealed a discourse of mutuality, in that both persons in the relationship went to have testing because it would be inequitable for only one to be tested. Other people saw HIV testing as part of a regime of regular body maintenance, similar to having a Pap smear test, but overlooked that it would not protect them against future infection. Lupton and colleagues also observed some interesting gender differences in testing. In particular, they noted that within the context of sexual relationships, women tended to be the instigators of testing, while men tended to see testing as an administrative hurdle required by their partners.

The role played by HIV testing in newly formed sexual relationships and the cessation of condom use has been observed in several other studies undertaken in Australia and the United States (Exner et al., 2002; Ransom et al., 2005; Van de Ven et al., 1997). Exner et al. (2002), for example, in a study of 360 heterosexual women aged 18-30 years who attended a family planning clinic in New York City, found that 26% of
women had last been tested for HIV because they had started a new relationship, while 15% had sought testing because they wished to stop using condoms with their current partner. Van de Ven et al. (1997), in a survey of tertiary students in New South Wales, Australia, over three successive years, found that the proportion of students who sought HIV testing within the context of an established sexual relationship substantially increased over the course of the study. In their final year of data collection, they report that 21% of students tested for HIV had done so at their partner’s request, while 8% had been tested at the start of the relationship, explicitly for the purpose of ceasing the use of condoms.

The similarities evident between the small body of research on hepatitis C testing and the larger body on HIV testing are not surprising given the similar role injecting drug use has in the transmission of these viruses. However, given the other major differences between the epidemiology of hepatitis C and HIV, in particular the role of sexual practices in transmission and the composition of affected populations (Crofts et al., 1999), the findings from the HIV literature may not generalise to hepatitis C.

1.2.8. Hepatitis C Testing Policy in Australia

An important factor in understanding patterns of hepatitis C testing in any country are the policies that regulate or guide its practice, as such policies typically outline who and how people should be tested for hepatitis C. In Australia, as it is in many European countries as well as Canada, testing is only one aspect of the broader public health response to the hepatitis C epidemic. This response proceeds from a harm reduction approach and includes other measures, such as needle and syringe exchange programs, methadone treatment, other forms of drug treatment and community education campaigns (Frankish, Moulton, Kwan, Waters & Buller-Talor, 2002; Hilton, Thompson, Moore-Dempsey & Janzen, 2001).

In all states of Australia the provision of pre- and post-test counselling to all people undertaking HIV testing is mandated. In Victoria, Australia, for example, this is under the Health Act 1958. This is however, not the case for hepatitis C. In light of the nature
of the infection, various departments and agencies have established policies and guidelines for best practice on the process of testing. These policies and guidelines are directly derived from the principles of HIV testing practices (McCoy et al., 2003). In Australia, guidelines for testing were first published by the National Health and Medical Research Council (NHMRC, 1997) within the document *A Strategy for the Detection and Management of Hepatitis C in Australia*. Although rescinded in 2002, this document continues to provide the basis for current testing protocol among services and agencies around Australia. Current testing guidelines are articulated in a number of sources, including the *National Hepatitis C Testing Policy* (ANCAHRD, 2003), the *Victorian Hepatitis C Strategy* (DHS, 2002), and guidelines provided to general practitioners by the Royal Australian College of General Practice (RACGP, 2003). These documents provide very similar guidelines on who should be tested for hepatitis C, the circumstances under which different types of tests (antibody or PCR) should be used and how testing should be performed, in particular, the provision of pre- and post-test counselling and discussion.

These policies indicate that hepatitis C testing should be routinely offered to anyone that displays a risk for hepatitis C that has been verified through scientific enquiry to be related to the transmission of the virus. The specific risks that warrant routine testing include engaging in injecting drug use, having been in prison or gaol, receiving a blood transfusion before 1990, receiving a blood transfusion or blood products outside of Australia, and experiencing an occupation exposure, such as a needle stick injury. Testing is also recommended for those with abnormal liver function tests or symptoms of hepatitis C, health care workers who engage in exposure-prone procedures, renal dialysis patients and anyone who requests a test but does not reveal a risk factor. These policies also suggest that testing may be offered to those who have a history of tattooing or piercing, were born in countries with a high population prevalence, or are the sexual partner of someone who is hepatitis C positive. Testing is not recommended, on the other hand, for those without an identifiable risk factor or an expressed desire to be tested, health care workers not involved in exposure prone practices, pregnant women, infants born to mothers who are hepatitis C positive, non-sexual or non-blood related
contact with a hepatitis C positive individual, pre-operative patients or the general population.

The guidelines for pre-test counselling and discussion include an assessment of scientifically verified risk factors, reasons for testing and social support mechanisms surrounding the testee; discussion of the natural history of hepatitis C, the window period, interpretation of possible results, prevention strategies, and issues surrounding confidentiality; and obtaining informed consent. The guidelines for post-test counselling and discussion vary slightly according to the result of the test but articulate the need for post-test counselling and discussion for all test results. If the test result is negative, prevention strategies and, if injecting drug use is identified, vaccination against hepatitis A and B, are discussed. If the test result is positive, reiteration of hepatitis C information, treatment options, disclosure of test results, psychological support, vaccination against hepatitis A and B, managing hepatitis C, and safe practices are discussed. Furthermore, if the result is indeterminate or equivocal – that is, either a positive result on the first sample and a negative on the second sample, or a weak positive on both samples – then the result should be repeated using a different testing kit. The practitioner is also instructed to explain the need to repeat the test and provide prevention information and support (ANCAHRD, 2003; DHS, 2002; NHMRC, 1997; RACGP, 2003).

1.2.9. Assumptions Underlying Australian Testing Policy

Hepatitis C testing is intended to fulfil several roles when conducted within the context of testing policies outlined above. First, it provides the testee with sufficient information for an informed decision to be made about whether they wish to be tested. Second, it intends to minimise possible negative outcomes due to undergoing a diagnostic test or receiving a positive test result. Third, it serves a preventive function (McCoy et al., 2003; Gordon, 1999). Although the discussion contained within the section is intended to apply to Australian policies presented in the preceding section, it can equally apply to any testing policy that includes pre- and post-test counselling and discussion as part of standard practice.
Testing is argued to serve a preventive role primarily through identifying those who are hepatitis C positive. These individuals can then modify their behaviour to reduce the likelihood of transmission to others (Gordon, 1999; Rhodes et al., 2001; Ziek, Goldstein, Beardsley, Deren & Tortu, 2000) and the likelihood of being infected with other hepatitis C genotypes (Crofts, Aitken & Kaldor, 1999). Positive individuals may also access treatment and modify their lifestyle to promote better health, for example reducing or avoiding alcohol (Gordon, 1999; Kwiatkowski, Corsi & Booth, 2002; Rhodes et al., 2001). Testing may also serve a preventive role with those who test negative, as these individuals may be counselled to modify their behaviour in an effort to reduce their risk of future infection.

The idea that testing, undertaken with pre- and post-test counselling, can serve a preventive role in the spread of hepatitis C and other blood-borne viruses has been criticised by many authors, as it assumes a linear relationship between testing, counselling and behavioural change (Beardsell, 1994). This assumption is challenged on a number of grounds: 1) there is currently insufficient evidence to support this relationship; 2) the research that is available is confounded by several methodological issues; 3) counselling is not delivered by health care workers or received by testees in a uniform manner; 4) testees’ motivations for testing are not identical; 5) information transfer alone is insufficient to elicit sustained changes in potentially health compromising practices; and 6) it fails to take account of the personal and social contexts that impact on testees’ potentially health compromising practices (Beardsell, 1994; Keys, Mallett & Rosenthal, 2006; Higgins et al., 1991). These points are discussed in greater detail below.

While previous studies, including those from the HIV/AIDS literature, indicate that testing and counselling may have some affect on potentially health compromising practices (Aitken, Kerger et al., 2002; Skipper, Guy, Parkes, Roderick & Rosenberg, 2003; Tucker et al., 2004; Weinhardt, Carey, Johnson & Bickham, 1999; Ziek et al., 2000), the specific effects of these protocols are unclear. Some studies have observed changes in sexual practices following testing coupled with counselling (Weinhardt et
al., 1999; MacGowan et al., 1997), while others have noted changes in injecting practices (MacGowan et al., 1997; Aitken, Kerger et al., 2002). Some authors have observed that changes in potentially health compromising practices are more pronounced in those who test positive than those who test negative (Weinhardt et al., 1999; Wright, Tompkins & Jones, 2005; Ziek et al., 2000), while others have found that such differences were not attributable to the outcome of the serological test (Aitken, Kerger et al., 2002; Beardsell, 1994). Notwithstanding the contradictory nature of such results, several methodological issues limit the reliability, validity and interpretability of these findings. The majority of the studies have lacked control groups, failed to report the period of time between receiving testing and counselling and follow-up, assessed practices at only two points in time (pre- and post-test), have relied solely on self-reported measures, and have typically utilised self-selected participants (Higgins et al., 1991). Moreover, there is little understanding regarding the specific components of the interventions that are effective (Dowsett et al., 2005), as the nature and content of the counselling sessions are typically unreported or not systematically examined.

The assumption that pre- and post-test counselling and discussion can serve as a preventive measure is also founded on the idea that it is delivered by health care workers and received or experienced by testees in a uniform manner. However, this may not be the case (Beardsell, 1994; Lindan, Avins, Woods, Hudes, Clark & Hulley, 1994; Loxley et al., 2000). This assumption ignores the fact that different health care providers may elicit widely different effects due to differences in profession, experience, training and time allotted to undertake counselling (Coyle & Soodin, 1992). Similarly, the experience of testees in receipt of counselling may not be uniform. In a series of studies, Loxley and colleagues found that testing for blood-borne viruses (including hepatitis C) was not a meaningful or positive experience for many injecting drug users in Australia. They report that injecting drug users often did not understand the meaning of the test results, in particular what a “positive” result indicated (Loxley, 1991 in Loxley et al., 2000; Loxley, 1998; Loxley, Carruthers & Bevan, 1995; Maher et al., 2001). Furthermore, a substantial proportion of injecting drug users report that they did not receive pre- or post-test counselling as part of testing (Ovenden & Loxley, 1993), a
response that has also been noted by other authors (Clark, Kahn, Gallagher & Schwarz, 2005; O’Brien et al., 2001).

Current hepatitis C testing policies also implicitly assume that the testees’ motivations for testing and motivation to change their practices are uniform. Specifically, it assumes that those who undergo testing have made a choice to be tested, undergo testing solely for medical or health-related reasons, and/or have a desire to change the practices that have caused them to require testing. This assumption ignores that some people who undergo hepatitis C and other blood-borne virus testing have, or feel they have, little choice in whether or not they are tested (for example, within prison or detention) (Loxley et al., 2000; Myers et al., 2005; O’Brien et al., 2001), that for some people, testing can serve a social rather than a medical function (Lupton et al., 1995), or that some may not desire or be in a position to change the practices in which they engage (Beardsell, 1994).

A significant component of the pre- and post-test counselling involves the transfer of information from health care worker to testee. It is assumed that the testee only engages in these behaviours through ignorance (Lupton, 1999b) and that the provision of relevant information will be sufficient to elicit immediate or sustained behavioural change. Previous intervention research, including that on HIV, reveals that knowledge-based interventions alone have little sustainable impact on behaviour change (Oakley et al., 1995; Rotheram-Borus, Mahler & Rosario, 1995; Slonim-Nevo, Auslander, Ozawa & Jung, 1996). Moreover, such interventions fail to take account of the personal and social contexts that impact on testees’ engagement in practices that are potentially health-compromising practices and that changes in such practices typically occur gradually over time and often with periods of relapse (Baer, Peterson & Wells, 2004; Beardsell, 1994; Prochaska, DiClemente & Norcross, 1992). Furthermore, it ignores other aspects which can either aid or impede changes in practices, such as gender, cultural background, income and poverty, housing stability, intoxication, mental illness, social support from partners, friends or service providers, positive outlook of the future, and positive self-esteem (Beardsell, 1994; Bourgois, Prince & Moss, 2004; Hogan, 2001; Higgs, Maher, Jordens, Dunlop & Sargent, 2001; Keys et al., 2006; Mallett et al.,
There are several limitations to the current literature on hepatitis C testing. First, as discussed throughout this chapter, there is currently very little research that has actually examined issues associated with hepatitis C testing, such as who is tested and why they are tested for hepatitis C. Gaining insight into these issues is important as it may lead to more tailored approaches towards testing, and more positive experiences and outcomes for the recipients of testing (Loxley et al., 2000). Current policies surrounding testing assume a single trajectory into testing, namely engaging in one or more of a small selection of so-called risk practices, identifying these practices as dangerous, and seeking testing as a consequence. This assumption may not accurately reflect the motivations and experiences of all of those who are tested for hepatitis C and may limit the usefulness of the testing experience for the recipient and broader public health concerns.

Second, all studies of hepatitis C testing thus far have employed cross-sectional designs, with very few having employed longitudinal designs. Cross-sectional research is particularly useful for obtaining descriptive information about phenomena and their correlates. They are typically much cheaper to undertake than longitudinal designs, allow for a more rapid dissemination of findings and, as participants are measured on only one occasion, are free from practice effects or other changes in participant behaviour as a consequence of their participation (Anstey & Hofer, 2003). Cross-sectional designs are however, limited to examining the association between testing and a range of variables and cannot assess change over time, the incidence of new cases of testing (as they occur), or whether a causal relationship exists between covariates and outcomes (Anstey & Hofer, 2003). Longitudinal designs, on the other hand, are able to examine these issues because they collect data from the same individual(s) at more than one point in time. Although these designs are not without methodological concerns, they provide a means of answering questions that cannot be answered in cross-sectional
designs. Further, because data are collected from the same individual(s), the problem of cohort effects (i.e. that observed differences between two samples may be due to characteristics of the samples rather than in the phenomenon of interest) inherent in cross-sectional studies are removed (Breakwell, Hammond & Fife-Schaw, 1995).

Third, the majority of studies have used samples of injecting drug users and, in particularly, those participating in drug treatment programs (Cook et al., 2001). The focus on injecting drug use is justifiable, given those individuals are most likely to contract hepatitis C infection in Australia, and other developed countries, and that significant reductions in the incidence of hepatitis C will only be possible through working with such individuals. The focus on those undertaking treatment for drug use, while perhaps done out of necessity to easily recruit participants, is problematic, as they are likely to differ from other drug users, and indeed the broader population, in several ways. For example, they have a desire (or need) to change their drug use behaviours and/or the magnitude of their drug problem is such that they require intervention. Given these differences, findings based upon such samples may not generalise to other populations.

One population among which little hepatitis C research has been conducted is young people who experience homelessness. This is surprising given that young people who experience homelessness are a socially and economically disadvantaged population that engage in many practices that can place them at risk of contracting hepatitis C (as will be discussed in greater detail in the next chapter). Furthermore, National Surveillance data indicates that younger people comprise the majority of cases of newly acquired hepatitis C (NCHECR, 2006). Indeed, the small number of studies undertaken in the United States that have examined hepatitis C among young people who experience homelessness confirm an increased prevalence (Beech, Myers & Beech, 2002; Diaz et al., 2001; Martins et al., 1995; Noell et al., 2001; Roy et al., 2001). There is also a report that the duration of homelessness, at least in Australia, may be related to hepatitis C prevalence, with higher rates among those who have been homeless for longer periods of time (Rosenthal et al., 2003).
Fourth, the majority of studies that have previously examined hepatitis C testing have typically used a small number of measures or covariates, primarily scientifically verified risk factors related to the transmission of the hepatitis C virus. Social and contextual factors, on the other hand, such as employment, education, living arrangements, and contact with the social service sector, have generally been excluded or ignored. These factors, however, may provide valuable insight into the characteristics of those who are tested for hepatitis C.

The final limitation to the current understanding of hepatitis C testing is that the majority of the research to date has exclusively used quantitative methods. Furthermore, the few studies that have used qualitative methods have used them in a limited manner; exclusively open-ended survey questions delivered in an interview format. Quantitative methods typically stem from a positivist or scientific paradigm and assume a reality that is objective and measurable. These methods have broad acceptance within the academic, applied and policy-related fields, as they are typically seen to provide an unbiased, reliable and valid measurement of phenomena under investigation. Quantitative methods enable the testing of hypotheses in a systematic manner and generalisations to be made to the larger population (Hathaway, 1995). Such methods, however, have a limited capacity to examine or account for the social, historical and cultural context within which issues, such as hepatitis C testing, occur and tend to simplify phenomena in an effort to provide empirical measurement and generalisability of findings (Bourgois, 2002; Lupton, 1999a; May, 2001; Rhodes & Moore, 2001a, 2001b).

Although a diverse collection of research strategies, qualitative methods provide a different but complementary approach to researching and understanding health and illness by enabling different types of research questions to be posed and different types of answers to be obtained. Qualitative methods provide a rich body of material that allow health issues to be examined from the participant’s experiences, rather than the “average” response of a group or the perspective imposed by the researcher (Bourgois, 2002; Chamberlain, Stephens & Lyons, 1997; Denzin & Lincoln, 2000; Hathaway, 1995). Moreover, while quantitative research relies on inferential and empirical
methods, qualitative research seeks to understand the participant’s interpretation of their own social environments. These methods are used when process and meaning is of interest, not amount, quantity, intensity or frequency (Denzin & Lincoln, 2000). While these techniques have been widely used within the disciplines of sociology, anthropology and social work, traditionally positivist, quantitative fields, such as psychology and medicine, are only beginning to embrace them (Chamberlain et al., 1997).

Furthermore, there has been increasing recognition of the value in using a combination of quantitative and qualitative methods in research programs, also called mixed methods or multi-methods approaches. Proponents of such approaches argue that the limitations inherent in either set of methodologies can be negated by the advantages of other set of methodology (Creswell, 2003; Hedrick, 1994; House, 1994). This thesis holds the position that neither broad group of methods is superior but that each is useful or appropriate in particular situations, dependent upon the particular research questions posed.

Recognising the several limitations of the previous research on hepatitis C testing, this thesis aims to enhance the present understanding of the human factors associated with hepatitis C testing by undertaking a detailed examination of the patterns of hepatitis C testing among young people who experience homelessness in Melbourne and how they relate to behavioural and contextual factors. Moreover, this thesis will examine the social, behavioural, psychological and environmental context in which hepatitis C testing occurs for young people who experience homelessness.

The following chapter continues to discuss previous research as a basis for undertaking this thesis. More specifically, it examines the meaning of risk, a term that underpins the majority of hepatitis C testing and infection research and policy, and introduces a population of people who are paradigmatic at-risk population, namely young people who experience homelessness.
Young People Who Experience Homelessness

2.1. Overview

Young people who experience homelessness are a much-studied population within the research literature, particularly in the United States. Typically labelled “homeless young people” or “homeless youth”, these young people are characterised by the majority of this research as a socially and economically disadvantaged population that engage in practices that place them at risk of contracting hepatitis C and other infections (AIHW, 2003; Bucy & Obolensky, 1990; Crane & Brannock, 1996; Ensign, 1998; Mallett et al., 2006; Robertson, 1992; Rotheram-Borus, Feldman, Rosario & Dunne, 1994). They are also often seen as vulnerable and in need of assistance but at other times, as dangerous individuals who need to be managed or controlled (Alaszewski, 1998; Bessant, 2002; Hagan & McCarthy, 1997; Rotheram-Borus et al., 1994). Data collected as part of the national Census of Population and Housing in 2001 indicated that approximately 1.4% of those aged 12-18 years in Australia, or 26,000 young people, were homeless on the night of the census. After accounting for increases in population and differences in methodology, this represents an increase of 8.4% from 1994. Similar proportions were noted in Victoria, with 4660 or 1%, of young people aged 12-18 years experiencing homelessness (Chamberlain & MacKenzie, 2002). Substantial increases in the population of young people who experience homelessness has also been noted in other Western countries, such as the United States (Ringwalt, Greene, Robertson & McPheeters, 1998; Robertson, 1991; Rotheram-Borus, Parra, Cantwell, Gwadz & Murphy, 1996) and Scotland (Anderson & Tulloch, 2000).

2.1.1. Definitions of Young People who Experience Homelessness

Definitions of young people who experience homelessness typically examine two elements: 1) what is a young person, and 2) what is homelessness. The way these elements have
been defined however, have varied considerably over time and between countries (Chamberlain & MacKenzie, 1998; Fopp, 1992, 1993; Mallett et al., 2006; Robertson, 1992).

The most frequently cited means of defining and identifying young people is by chronological age. There is little consensus between researchers and policy makers however, on the precise age boundaries of what constitutes a young person (Gross & Capuzzi, 2000; Mallett et al., 2006). The United Nations, since declaring International Youth Year in 1985, defines a young person as someone between the ages of 15 and 24 years (Department of Economic and Social Affairs, 2005). The age boundaries used within the research and academic literature in Australia, and other developed countries, is highly variable and typically inconsistent with the UN definition. The lower age limit tends to range from 12 to 16 years, while the upper age limit tends to range from 18 to 30 years, although most commonly up to the mid-twenties (≈ 25 years). Similar diversity in age boundaries also exist within the services, departments and policies charged with the care and management of young people. In Australia (Mallett et al., 2006) for example, the Supported Accommodation Assistance Program (SAAP)\(^7\) typically defines a young person as an individual aged 12-24 years (AIHW, 2003), while the Reconnect program\(^8\) targets young people aged 12-18 years (DFaCS, 2004).

The most frequently used definition of homelessness, particularly among young people, stems from the large volume of research undertaken in the United States that centres on typologies. This approach dominates research and service provision to these young and has also been enshrined in law regulating young people’s behaviours in the United States, such as the *Juvenile Justice and Delinquency Prevention Act 1974*. A number of typologies have been described (de Man, Dolan, Pellerier & Reid, 1993; Ensign, 1998; Ringwalt, Greene & Robertson, 1998; Rotheram-Borus, Koopman & Ehrhardt, 1991; Tomb, 1991) however, they too are inconsistently defined and used between

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\(^7\) SAAP is the primary source of funding for crisis and transitional accommodation for people experiencing homelessness in Australia. SAAP is jointly funded by Federal, State and Territory governments (Department of Family and Community Services [DFaCS], 2004).

\(^8\) Reconnect is a federally funded early intervention program targeting young people who experience homelessness and young people at risk of homelessness in Australia. The Reconnect programs aim to increase young people’s engagement with their family, educational institutions, employment and other forms of community participation (DFaCS, 2004).
departments and researchers. Furthermore, the usefulness of the typology based approach is increasingly questioned, even in the United States, given the considerable overlap between the categories (Greene et al., 2003; Rotheram-Borus, Mahler, Koopman & Langabeer, 1996; Tomb, 1991). Notwithstanding this opposition, they are still heavily used.

The most frequently used homeless types are the “homeless”, “runaway” and “throwaway” youth (Ensign, 1998; Greene et al., 2003; Tomb, 1991; U.S. Department of Justice, 2002; Zide & Cherry, 1992). A homeless youth refers to a young person who lacks stable living arrangements and is unaccompanied by their parent(s), guardian(s) or caregiver(s) (Greene et al., 2003), while a runaway youth is seen as a young person who has voluntarily chosen to leave home (Ennett, Federman, Bailey, Ringwalt & Hubbard, 1999; Ensign, 1998; Greene et al., 2003; Greenblatt & Robertson, 1993; Gullotta, 1978; Rotheram-Borus, Parra et al., 1996). In the research literature, runaways are sometimes separated into “running from” and “running to” youth (Sharlin & Mor-Barak, 1992; Tomb, 1991), which distinguishes between those who are actively escaping an intolerable situation and those who initially leave home to assert independence, escape boredom, seek excitement or because of the allure of the street, respectively. The third major type – throwaway youth – defines young people who have either been encouraged to leave home or has been forcibly ejected from their home by a parent, guardian or caregiver (Greene et al., 2003; Tomb, 1991).

Several other typologies have been used within the US empirical literature and include: “system kids”, those who have a history of contact with social services (e.g. foster families) and have left a problematic placement; “street youths” or “street children” those who lack basic shelter and are currently living in public places, such as parks, bus shelters or abandoned buildings; “shelter kids”, those staying in emergency accommodation, such as refuges crisis-accommodation or transitional housing; and “near-homeless”, sometimes called “couchers” or “couch surfers”, those who are

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9 This category is also particularly prominently in the South American research (e.g. Inciardi & Surratt, 1998; Martins et al., 1995; Monteiro & Dollinger, 1998) because of the prominence of these living arrangements among young people who experience homeless in this region.
temporarily living with friends, relatives or partners because they have nowhere else to live (Bucy & Obolensky, 1990; Ensign, 1998; Rotheram-Borus, Koopman et al., 1991; Rotheram-Borus, Rosario & Koopman, 1991; Zide & Cherry, 1992).

The way homelessness is defined in Australian public debate and policy development is different to the way it is in the United States. The most influential conceptualisation is that developed by Chamberlain and Mackenzie (1998, 2002) and has been adopted by agencies and departments, such as the ABS and the Department of Human Services, Victoria. Chamberlain and Mackenzie assert that homelessness is a socially constructed concept that varies depending upon the specific community and historical era in question and stems from shared community values about minimum standards of housing or adequate housing. These standards are embedded in community housing practices of the day and are defined as the minimum that can reasonably be obtained in the private rental market; in Australia they argue this is “a small flat with a bedroom, living room, bathroom and kitchen secured by a lease arrangement” (Chamberlain & Mackenzie, 2002, p.4).

According to their conceptualisation, three ordinal categories of homelessness – primary, secondary and tertiary – can be described. Primary homelessness refers to those without shelter and includes people who live in public spaces, such as street or parks, derelict buildings and cars. Secondary homelessness refers to people with only temporary living arrangements and who do not have secure housing elsewhere. This category includes those living at a relative’s or friend’s home, and crisis accommodation services. Tertiary homelessness refers to those who are live for long periods in single room boarding houses. They are considered homeless, to Chamberlain and Mackenzie, because the majority of these dwellings do not meet their definition of the community’s minimum standard of housing (Chamberlain & Mackenzie, 1998, 2002).

There is increasing recognition in Australian and UK debates about homelessness that the trajectory of homelessness is extremely varied, rather than, being a fixed state or event, as implied in the majority of research on these young people (Anderson &
Tulloch, 2000; Chamberlain & MacKenzie, 2004; Fitzpatrick, 1999; Fitzpatrick, Kemp & Klinker, 2000; Mallett et al., 2006). Although some young people who become homeless remain so for long periods of time, many young people remain homeless for only short periods of time and/or move in and out of being homeless multiple times before attaining stable accommodation (Mallett et al., 2006; Milburn Ayala, Rice, Batterham & Rotheram-Borus, 2006). The recognition of the varied trajectory of homelessness is said to have important implications for the service provision to these young people, as different service types are required at different points of the homelessness trajectory (Chamberlain & MacKenzie, 2004).

To acknowledge the varied trajectory of homelessness, the phrase “young people who experience homelessness” is used throughout this thesis instead of the more conventional labels, homeless young people or homeless youth. This phrase is preferred as it emphasises that these young people are only currently experiencing the state of being homeless, rather than homelessness being a fixed or permanent state or characteristic. It is also used because it emphasises that these individuals are young people firstly, rather than homeless. Moreover, many who experience homelessness do not identify themselves as homeless even though they do not have stable accommodation (Chamberlain & MacKenzie, 1998; Ringwalt, Greene, Robertson & McPheeters, 1998; Robertson, 1992).

2.1.2. Research on Young People who Experience Homelessness

The current understanding of young people who experience homelessness in Australia has been heavily influenced by the wealth of cross-sectional research undertaken in urban environments within the United States. There has been a small amount of research conducted in Europe – mainly the United Kingdom – that has primarily focused on housing pathways (Anderson & Tulloch, 2000; Fitzpatrick, 1999). It however, has currently had little influence over Australian debates. The majority of the domestic and international research is also dominated by epidemiological, medical and psychological perspectives. This research focuses on young people’s problems, rather than their strengths or capabilities, and frames them as a homogenous at-risk population (Moore,
2002; Wyn & White, 1997). They are considered at-risk because of their state of homelessness and the practices typically associated with those who are homeless. They are viewed as more likely to engage in risky practices because of their social and economic background but also because of the culture of homelessness in which they are presumed to be part. Furthermore, young people who experience homelessness are considered at-risk because of the transitional stage or phase of life they occupy.

The majority of the risk-based research on these young people has focused on drug use and sexual practices and the implications of these practices on their health, particularly for HIV (e.g. Booth & Zhang, 1997; Ennett et al., 1999; Halcón & Lifson, 2004; Johnson, Aschkenasy, Herbers & Gillenwater, 1996; Rotheram-Borus et al., 1994; Van Leeuwen et al., 2004). Many other studies have profiled these young people’s physical, mental, sexual and reproductive health, family background, exposure and involvement in violence and assault, and participation in employment and education.

The catalogue of risk produced and/or perpetuated by this stream of research indicates that young people who experience homelessness are more likely than home-based young people to use illicit drugs, inject illicit drugs, engage in unprotected sexual activity and/or sexual activity with multiple partners, and spend time in gaol (Hillier, Matthews & Dempsey, 1997; Inciardi & Surratt, 1998; Rosenthal, Moore & Buzwell, 1994; Rosenthal, Mallett, Milburn & Rotheram-Borus, in press; Rossiter et al., 2003; Rotheram-Borus & Koopman, 1991; Rotheram-Borus, Koopman et al., 1991). Young people who experience homelessness are more likely to experience physical illness (Ensign, 1998, 2003; Howard, 1995; Klee & Reid, 1998a; Reid & Klee, 1999), exhibit elevated levels of psychological distress, and report having been diagnosed, either currently or during their lifetime, with a psychiatric disorder, particularly mood and anxiety related disorders, substance use and abuse disorders and psychotic disorders (Fuller, Krupinski, Krupinska, Pawsey & Sant, 1994; Kamieniecki, 2001; Kipke, Montgomery, Simon & Iverson, 1997; Koopman, Rosario & Rotheram-Borus, 1994; Rew, 1996; Robertson, 1992; Rosenthal, Mallett, Gurrin, Milburn & Rotheram-Borus, 2007; Shane, 1991). Young people who experience homelessness are also more likely than home-based young people to have attempted suicide and deliberately harmed
themselves without the intent to kill (Cullum et al., 1995; Dadds, Braddock, Cuers, Elliott & Kelly, 1993; de Man et al., 1993; Fuller et al., 1994; Greenblatt & Robertson, 1993; Greene & Ringwalt, 1996; Howard, 1995; Klee & Reid, 1998a; Molnar, Shade, Kral, Booth & Watters, 1998; Rotheram-Borus, 1993; Shane, 1991; Yoder, 1999).

Young people who experience homelessness are more likely than those living at home to become pregnant or have children (or their partner, if male) (Greene & Ringwalt, 1998; Howard, 1995; Pennbridge, MacKenzie & Swafford, 1991; Rossiter et al., 2003). The prevalence of HIV and most sexually transmitted infections is high among young people who experience homelessness and much higher than home-based young people (Adlaf, 1999; Auerswald, Sugano, Ellen & Klausner, 2006; Cauce et al., 1998; Clements, Gleghorn, Garcia, Katz & Marx, 1997; Forst, 1994; Goodman & Berecochea, 1994; Kamieniecki, 2001; MacDonald, Fisher, Wells, Doherty & Bowie, 1994; Mallett et al., 2003; Pinto et al., 1994; Rew, Fouladi & Yockey, 2002; Rossiter et al., 2003; Rotheram-Borus et al, 1994; Rotheram-Borus et al., 2003).

Although young people who experience homelessness come from diverse family backgrounds, their families are routinely characterised as fractured, dysfunctional and physically, sexually or emotionally abusive (Ayerst, 1999; Brown, 1993; Dadds et al., 1993; de Man et al., 1993; Doyle, 1996; Feitel, Margetson, Chamas & Lipman, 1992; Greenblatt & Robertson, 1993; Ringwalt, Greene & Robertson, 1998; Whitbeck, Hoyt & Ackley, 1997a, 1997b; Whitbeck & Simons, 1993; Wolfe, Toro & McCaskill, 1999). They are more likely to have histories involving contact with child protection agencies (Klee & Reid, 1998a; Myers, Mallett & Rosenthal, 2003). Young people who experience homelessness are also more likely than home-based young people to have experienced recent physical and sexual violence (Brown, 1993; Doyle, 1999; Ennett et al., 1999; Kipke, Simon, Montgomery, Unger & Iversen, 1997; Kurtz, Kurtz & Jarvis, 1991; Powers, Eckenrode & Jaklitsch, 1990; Rosenthal & Mallett, 2003; Rotheram-Borus, Mahler et al., 1996; Shane, 1989; Terrell, 1997; Tyler, Hoyt & Whitbeck, 2000; Whitbeck et al., 1997b; Whitbeck & Simons, 1993).
Young people who experience homelessness are often in an economically disadvantaged position. They are less likely than home-based young people to be employed but more likely to rely on government financial support or engage in alternative, often illegal, means of generating income (Chamberlain & MacKenzie, 1998; Clatts & Davis, 1999; de Man et al., 1993; Mallett et al., 2006; Rossiter et al., 2003). Moreover, they often have limited opportunities for paid employment because of their educational histories (Goldman & La Castra, 2000). They are less likely than young people living at home to currently be in education or to have graduated from high school (Clatts & Davis, 1999; Kral, Molnar, Booth & Watters, 1997; MacKenzie & Chamberlain, 1995, 2002; Mallett et al., 2003; Robertson, 1991). Young people who experience homelessness also tend to have poor academic records and more frequently report school-related behavioural problems (Robertson, 1992; Weiner & Pollack, 1997).

The notion of risk underpins how young people who experience homelessness are typically understood, as well as the current understanding of and response to hepatitis C testing and infection, as discussed in Chapter 1. The notion of risk typically involves the quantification of risk factors and targeting those deemed at-risk with preventive measures, such as testing or education. Although the term is frequently used within these contexts, the nature of risk and the assumptions implicit in its use are infrequently debated or critiqued. The following section discusses the major ways in which risk is conceptualised and how they have been and/or can be applied to the study of hepatitis C testing and infection, homelessness and young people. It should again be noted that this thesis is not about risk but rather, it is discussed because it is an inescapable concept in these fields and has dominated the way in which the issues of interest to this thesis are understood.

2.2. What is Risk?

Risk is an extremely powerful idea that emerged during the mid to late twentieth century to become a dominant discourse in the way people in many Western societies understand and respond to their social world (Beck, 1992; Fox, 1999; Giddens, 1991; Lupton, 1999a; Peterson & Lupton, 1996; Rhodes, 1997). The idea of risk pervades...
almost every aspect of our lives (e.g. economics, politics, relationships, engineering, insurance, and road safety), although its importance is not always acknowledged (Alaszewski, 1998; Jeager, Renn, Rosa & Weber, 2001; Lawy, 2002).

The influence and dominance of the discourse of risk is no more evident than in the study of health and illness (Baum, 1998; Peterson & Lupton, 1996). The review of the research literature on any health issue yields a myriad of publications concerned with identifying and cataloguing risk factors or risky behaviours, describing and predicting at-risk groups, and evaluating and promoting risk reduction or risk prevention strategies. Such risk-based accounts of health and illness have also had significant influence in shaping public health policies and health practitioners’ practice. Within this literature and, indeed, the broader social science field, young people have been singled out, although not exclusively\(^\text{10}\), as an at-risk group in need of monitoring and protection (Moore, 2002; Wyn & White, 1997). Moreover, young people who experience homelessness are the quintessential at-risk population of young people because they are a group of young people seen to be most likely to engage in risk practices and experience negative outcomes associated with these practices. How then is risk understood?

Although a commonly used term, the notion of risk is ambiguous and value-laden. There are many different ways in which risk is defined and understood. Moreover, these different ways implicitly reflect the ontological and epistemological positions of those employing the term. The modern everyday meaning of risk refers to the chance of a negative event or events occurring. *The Australian Concise Oxford Dictionary* (1996), for example, defines risk as “a chance or possibility of danger, loss, injury, or other adverse consequences”. The everyday definition of risk has been linked to the probability of negative events since it entered the English language but early usage also referred to chance of events occurring or the balance between loss and gain (Alaszewski, 1998). Within the social sciences there are two main perspectives –

\(^{10}\) Other singled out at-risk groups include, but are not limited to, men who have sex with men, injecting drug users, Indigenous populations, sex workers, and refugees.
positivist and sociocultural – from which risk is defined and understood (Lupton, 1999b).

2.2.1. Positivist Perspective

The positivist or scientific ontological position is arguably the most influential way in which risk is defined and understood. This perspective has had significant influence on the everyday definition of risk and holds that risk is the probability or chance of a negative event(s) or outcome(s) occurring (Alaszewski, 1998). Risk is assumed to be an objective (pre-existing), measurable and uncontested phenomenon. Proponents of this perspective are principally concerned with identifying and cataloguing risks, determining the magnitude of risks, and the accuracy with which risk is identified and measured. The outcomes of these investigations are typically then used to develop ways of managing risk, such as through prevention and intervention measures. These accounts of risks have also had significant influence on public health policies (Alaszewski, 1998; Lupton, 1999b; Jaeger et al., 2001; Rhodes, 1997), such as those relating to hepatitis C testing discussed in the previous chapter, by providing a language with which to discuss health issues (e.g. risk factors, at-risk groups) and prioritising particular aspects of health issues for intervention or management.

Linked to the positivist version of risk is the idea of the rational actor (Alaszewski, 2005; Lupton, 1999b). Broadly speaking, this idea assumes that humans are active and autonomous decision-makers who choose particular actions or options that best meet their goals and, therefore, increase their happiness. Specific decisions are made based on the outcome of a risk/benefit analysis using information available (Renn, Jaeger, Rosa & Webler, 2005). Accordingly, avoiding risk is seen as rational and engaging in risk is seen as irrational (Lupton, 1999b). In the context of health and health management, a rational actor will seek to improve his/her health and minimise negative impacts on health because it is viewed as an essential component to human happiness and well-being (Alaszewski, 2005; Jaeger et al., 2001). A person who engages in risk practices, on the other hand, is viewed to either be engaging in irrational behaviour or doing do only because they are is ill-informed about the risky nature of their practices.
The role of experts, such as doctors, scientists and politicians, in disseminating relevant information regarding risk (as deemed by the expert) is conceived as critical. Although individuals are held to be free agents in their decision-making, they are paradoxically also portrayed as passive in the receipt of information. They are seen to unquestioningly accept this information because it is sourced from an expert. Should the recipient be deemed by the expert to not use the risk information effectively, it is for the expert to work harder to convey the information about risk to ensure they do, through, for example, reframing the relevant information or altering the mode in which the information is delivered (Alaszewski, 2005).

Several theories have been developed in regard to how rational action specifically relates to health-related decision making and provides a foundation, particularly within the discipline of psychology and medicine, to how health behaviours are understood. Two of the most prominent theories are the Health Belief Model (HBM) and the Theory of Planned Behaviour (TPB). These models are similar in their assumptions of a rational actor and the role of experts in communicating risk information but vary in ascribing the antecedents of specific action taking.

2.2.1.1. Health Belief Model

The HBM (Becker, 1974; Rosenstock, 1974) holds that individuals will make health-related decisions based upon a rational evaluation of relevant knowledge. The decision is said to be influenced by perceived susceptibility or vulnerability to the health issue, perceived efficacy of the interventions, consequences of not acting and a belief that the benefits outweigh the losses (Abraham & Sheeran, 2005; Lupton, 1999b; Moore & Rosenthal, in press). The model also assumes that knowledge regarding the risks and consequences of health conditions will automatically lead an individual to seek protection (Beardsell, 1994).

The HBM has been applied to a wide range of health issues including an array of health promoting and health compromising practices, adherence to medical treatment and
attendance at clinical services (Abraham & Sheeran, 2005). This model has not been directly applied to hepatitis C testing, although it has been applied to HIV (e.g. Dorr, Krueckeberg, Srathman & Wood, 1999; Maguen et al., 2000) and STI testing (Simon & Das, 1984). According to the HBM, a decision to be tested should follow if an individual believes they are susceptible to infection, believes the hepatitis C is severe enough to warrant action, are convinced of the benefits of being tested and believes there are few barriers to impede testing (Dorr et al., 1999).

2.2.1.2. Theory of Planned Behaviour

The TPB (Azjen, 1991) and it predecessor, the Theory of Reasoned Action (Azjen & Fishbein, 1980; Fishbein & Azjen, 1975), holds that intention to engage in a particular health promoting behaviour is the most important predictor of whether an individual will engage (or not) in the particular behaviour. Intentions are in turn said to be influenced by attitudes towards the behaviour (which are formed from their beliefs and knowledge of the behaviour), subjective norms, which reflect other’s beliefs about the behaviours and the individual’s motivation to accept and comply with these norms, and personal behavioural control, whether the individual believes it is easy or difficulty to engage in the particular behaviour (Beardsell, 1994; Conner & Spark, 2005; Moore & Rosenthal, in press).

As with the HBM, the TPB has been applied to many health practices, in particular, drug use, sexual contact, physical activity and exercise, and road safety (Conner & Spark, 2005). A number of studies have specifically looked at screening practices, such as cervical or breast screening, in relation to the TPB, although none have examined testing practices for blood-borne viruses or STIs. The application of the TPB however, would suggest that a young person is likely to engage in hepatitis C testing when their intention to be tested is high. Their intention to test would be predicted by a number of factors including a positive attitude towards testing. Attitudes to testing are derived from beliefs about the effectiveness of testing, the balance between perceived benefits (e.g. knowing their serostatus for themselves or others) and disadvantages of testing (e.g. anxiety or fear associated with having a test and/or receiving a positive diagnosis
of infection), and perceived stigma associated with infection. A young person’s intention to test would also be influenced by significant other’s, such as parents, friends, and sexual partners, appraisal that testing is a beneficial experience/procedure and the young person’s motivation to comply with other’s beliefs. The final influence on intentions to test are perceived barriers, such as knowing where to access testing, ability to get to a medical clinic and meeting the potential costs associated with testing (Conner & Spark, 2005; Moore & Rosenthal, in press).

2.2.1.3. Limitations of the Positivist Perspective

The positivist or scientific perspective on risk provides only a limited framework from which to understand how and why people engage in potentially health compromising or health promoting practices. It solely equates risk with the probability of negative outcomes, such as likelihood of engaging in injecting drug use or contracting hepatitis C, and generally fails to take account of, or even recognise, the sociocultural contexts in which such risk practices take place (Alaszewski, 1998; Bourgois, 2002). Understanding the broader context in which risk occurs can potentially lead to the development of more tailored prevention and intervention measures. It also enables more positive experiences and outcomes for recipients of such intervention measures, while also addressing broader public health concerns, such as preventing the spread of an infection or disease within a community (Loxley et al., 2000).

This version of risk typically displaces the responsibility of health onto the individual, that is, it is the individual’s responsibility to avoid risk and, conversely, their fault for engaging in risky practices (Bessant, 2000, 2002; Peterson & Lupton, 1996). This version of risk is also sometimes viewed as effecting control over individual action. Individuals are blamed and held solely accountable for their circumstances or practices that are deemed socially unacceptable (Lupton, 1993). For example, people who are obese are often labelled “fat” because they do not comply with ideal standards of health behaviour, such as regulating their dietary intake or participating in sufficient exercise (Peterson & Lupton, 1996), while people who use drugs are sometimes derogatorily called “junkies” because they are engaging in injecting drug use; an illicit and
potentially health compromising practice. The moral element of engagement in putative risk practices has meant, according to some authors, that the notion and category of risk has simply replaced older negative categories, such as delinquency and maladjustment (Bessant, 2000, 2002; Fox, 1999; Lupton, 1993). Those, for example, once labelled delinquent or deviant for engaging in illicit drug use and other socially stigmatised practices are now simply labelled as at-risk for engaging in the same practice (Bessant, Sercombe & Watts, 1998; Moore, 2002).

The assumption that people make rational decisions in relation to their health is often misplaced (Alaszewski, 2005; Beardsell, 1994; Jaeger et al., 2001). A number of studies have indicated that people are not passive recipients of health information and will not always respond to information rationally (e.g. Carrier, Laplante, & Bruneau, 2005; Thirlaway & Hegg, 2005). Some people actively look for and use particular information, while also actively avoiding others (Alaszewski, 2005; Beardsell, 1994). Moreover, some people are sceptical of expert knowledges altogether because of the apparent frequent contradiction between experts within the same field of knowledge (Beck, 1994, 1996; Duff, 2003). This account of risk also ignores that there may be many seemingly rational reasons for behaving “irrationally”, for example, not using condoms because they are disliked despite the risk of HIV (Beardsell, 1994).

The specific positivist or scientific models to explain health practices typically have poor predictive power. The HBM has been found to be a relatively weak predictor of health practices more generally (Beardsell, 1994). The few studies to specifically examine HIV testing (as none have examined hepatitis C testing) show similarly unremarkable results. Dorr et al. (1999) in a survey of 111 college students in the United States found moderate support for a relationship between perceived benefit and consideration of future consequences in predicting testing. Other measures theoretically related to test decision-making, namely perceived susceptibility, severity, barriers and norms, however, received no support. Other studies undertaken in the United States have found perceived susceptibility to be positively related to HIV testing (Pugatch et al., 2001; Maguen et al., 2000), while one study among young people who experience homelessness found it to be negatively related (de Rosa et al., 2001).
The TPB also struggles to successfully predict health related decision-making, particularly among young people (Moore & Rosenthal, in press). The main problem lies in the link between intention and action. Many studies, particularly those centring on safe sex practices, have demonstrated a large difference between deciding to do and actually undertaking a particular course of action (Boldero, Moore & Rosenthal, 1992; de Visser & Smith, 2001, 2004; Freese, 1995; Rosenthal, Fernbach & Moore, 1997; Sheeran & Orbell, 1998). Moreover, both the HBM and TPB ignore the observation that the ability to make rational decisions may be limited or altered by many factors both structural and individual, such as gender, income and poverty, housing stability, intoxication, mental illness, social support from partners, friends or service providers, positive outlook of the future, and positive self-esteem (Beardsell, 1994; Bourgois et al., 2004; Hogan, 2001; Keys et al., 2006; Mallett et al., 2003; Rayner, 2003; Rotheram-Borus et al., 1995).

2.2.2. Sociocultural Perspectives

Alternative views to the positivist perspective of risk broadly fall within three main sociocultural perspectives: cultural or symbolic, “risk society”, and “governmentality” (Lupton, 1999a, 1999b). These perspectives proceed from a social constructionist perspective and claim that the way in which risk is understood and negotiated is dependant upon the specific social and cultural context in which it is observed. These perspectives do not endeavour to make distinctions between what is a real or false risk but, rather, argue that risk is a product of perception and social-cultural processes or understanding. These perspectives also claim that it is more important to understand the ways in which risk is understood, constructed and acted upon than the extent to which it can be accurately measured (Adam & van Loon, 2000; Beck, 2000; Dean, 1999; Lupton, 1999b).

In the current pool of published literature, sociocultural theories on risk have not yet been specifically applied to hepatitis C testing. A specific sociocultural theory is not adopted in this thesis, however they are discussed here because they provide a
framework from which to critique the version of risk that has directly informed hepatitis C testing research and policy. There are a number of commonalities between these theories that are important to the discussion of hepatitis C testing. These include the recognition that the way in which risk is understood has dramatically changed in modern Western societies to the extent that it has become an extremely important, if not essential, aspect of the way individuals and institutions understand and negotiate their world. The modern incarnation of risk has also evolved to become a means of monitoring and regulating populations. It is linked to notions of blame, agency and responsibility, and is generated and reinforced through experts and expert knowledges (Lupton, 1999b). The following subsections outline the principles of each of these theories and how they may be used to understand risk in the context of hepatitis C testing.

2.2.2.1. Cultural or Symbolic

The cultural or symbolic perspective is one of the earliest modern theories on risk and was advanced by the eminent anthropologist Mary Douglas. It is based on her earlier work concerning purity and contamination and how these ideas are used to establish and maintain boundaries between the self and other individuals or groups (Douglas, 1966). Douglas argues that individuals or groups that are identified as dangerous, or a source of contamination, are labelled “Other” and seen as a threat to the social order (Lupton, 1999a). These ideas are shared conventions or expectations, rather than individual judgements, and are culturally specific; what is dangerous or threatening to one culture may not be seen as dangerous, or seen as dangerous in different ways, to another culture.

According to the cultural or symbolic perspective, risk is an extension of these ideas. It is a source of blame and used to establish and maintain social boundaries (Lupton, 1999b). Groups or institutions which threaten the safety of an individual or to the community as a whole are identified and labelled risky; by doing so they become Other (Douglas, 1986). The idea and label of risk is also used to provide an explanation of negative events that occur in daily life, much the way that the idea of sin had in pre-
modern Western societies or some non-Western societies today. Furthermore, Douglas argues that risk has become the dominant discourse of the Other in modern and late-modern societies because of its focus on individual responsibility, a characteristic said to be of modern societies, and its association with scientific neutrality (Douglas, 1982; Lupton, 1999b).

In the context of hepatitis C testing, the cultural or symbolic perspective on risk would hold that testing serves as a tool for detecting those who have engaged in socially deviant behaviours; in a similar way to how HIV testing has been interpreted by some authors (Lupton, 1993; McCombie, 1986). Individuals requiring testing are seen to have deviated from socially and morally acceptable codes of behaviour, by engaging in, for example, drug use or tattooing and skin piercing that is performed in unsafe environments. As a consequence, they are considered at risk for infection. Individuals who are observed to deviate from the norm become Other and are viewed as posing a threat to the health and safety of the community. They are further blamed for the burden they represent to the health care system as a result of actions they should have avoided. Interestingly however, testing policies do include risk factors for which blame can not be attributed, for example, receiving a blood transfusion before 1990 and exposure in the health care setting, such as through a needle stick injury. The primary focus of the implementation of hepatitis C testing policy however, has been on those who inject illicit drugs.

2.2.2.2. Risk Society

The risk society perspective has its origins in the works of Ulrich Beck and Anthony Giddens and describes how risk is constructed in late-modernity. It is particularly interested in the macro-structural processes that have lead to the dominance of a risk discourse in late-modern Western societies (Lupton, 1999a). The risk society perspective holds that the magnitude of dangers associated with late-modernity are uniquely different to other periods in history. Dangers have become greater in scale and more widespread; they have become globalised and, as a result, have become more difficult to avoid or manage.
The level of risk inherent in late-modern living has lead to a greater general awareness of risk, as individuals are forced to identify and manage them a daily basis. Through this process they are also said to have become “reflexive”. This is the first key concept of the risk society whereby individuals are seen to move towards a stance of critical self-reflection or reflexivity (Beck, 1996; Beck & Beck-Gernsheim, 2002). In particular, people have become critical of the outcomes or path of modernity and industrialisation, which, unlike other periods in history, are believed to have produced the very dangers from which people feel threatened, such as pollution, radiation, global warming or depletion of the ozone layer. Moreover, institutions, such as government, industry and science, are considered to be among the main producers. The general population is argued to have also become highly sceptical of knowledge provided by experts in relation to these risks, as scientific evidence is often regarded as contradictory or incomplete (Beck, 1994, 1996; Lupton, 1999b).

Risk society proponents are particularly critical of the risk discourse prominent in late-modern societies because it is inextricably linked to individual action and responsibility. “Individualisation”, a product of reflexivity, is the second key concept of the risk society thesis and refers to peoples’ shift towards thinking of themselves and being seen by others as free autonomous agents (Beck, 1992, 2002; Beck & Beck-Gernsheim, 2002). Individuals are viewed as making their own choices but also carry the expectation or responsibility to choose the right path (Lupton, 1999a). For Beck and Giddens, individualisation has resulted from the breaking down of traditional norms and values in the way people construct and understand their environment and self-identity (Beck, 1992). Within the context of risk, individuals are seen as having a high degree of control over their exposure to risks or dangers and thus, have a responsibility or burden to avoid and manage them (Lupton, 1999b).

Within the realm of health promotion, the ideas of choice, reasonability and self-monitoring are prominent (Keogh, 2003). People are urged to reflect on their own behaviours and to avoid or modify those that contribute to negative outcomes, such as eating less fat, increasing exercise, avoiding tobacco and not using illicit drugs
(Peterson & Lupton, 1996). Even from a harm reduction model, as applied to drug use, which recognises that those who currently use drugs are unlikely to cease consumption in the near future (Ksobiech, 2006), concentrate on ways to minimise the harm associated with these practices, such as not reusing needles or syringes, sharing needles or syringes with others, and not injecting alone (Jauffret-Roustide et al., 2006). The requirement or need for testing for hepatitis C is a signal that the process of self management has collapsed. Ironically, testing can also be seen as a reflexive action – the individual has reflected on their behaviours, deemed them risky and has chosen a means to manage the association risks.

2.2.2.3. Governmentality

The third major socio-cultural perspective on risk focuses on the idea of governmentality and draws on the work of Michael Foucault (1991). This perspective is primarily interested in how the idea of risk is constructed and normalised in late-modern societies and how it is used as a means of monitoring and managing populations (Lupton, 1999a). Several ideas are linked to this interpretation of risk including voluntary self-regulation (similar to individualisation in the risk society), the role of experts and “normalisation”.

Neo-liberal democratic governments, the dominant form in late-modern societies, are said to seek to rule their citizens through voluntary self-regulation rather than through coercive or violent means. The discourse of risk is a pervasive means of exerting disciplinary power over citizens to ensure they voluntarily engage in desired codes of action or behaviours (Lupton, 1999b). The construction of risk is also linked to the idea of experts and expert knowledges. Experts are held responsible for the construction and perpetuation of knowledge that provides the basis from which individuals can guide their actions (Lupton, 1999a). Central also to the neo-liberal style of governance is the process of normalisation, which refers to the method by which populations and individuals are compared to current norms of behaviour to determine how best they fit. Those who deviate from established norms tend to be identified as people in the state of
being at-risk rather than as people who engage in particularly risky practices (Lupton, 1999b).

Hepatitis C testing can be seen as one component of the system of power that seeks to regulate the population, particularly those who have already engaged in potentially health compromising practices, that is those deemed at-risk. In a similar way to that argued from a cultural or symbolic perspective, testing, for the governmentality theorist, also acts as a device for detecting those who have already chosen to deviate from normalised codes of behaviour, which have been defined by expert knowledges. Testing for hepatitis C, as it is performed in Australia, aims to redirect those who have strayed from accepted and expected norms of behaviour onto the correct path through providing prevention messages and information.

2.2.2.4. Limitations of Socio-cultural Perspectives

Although sociocultural perspectives broaden the analysis of how risk is understood and provide an alternative perspective to the positivist conceptualisation, they have a number of limitations. First, these perspectives can obscure the fact that some individuals, including young people and especially those who experience homelessness, do engage in practices that can compromise their health, such as sharing needles and syringe when injecting drugs and unprotected sex, which can lead to hepatitis C and other infections (Chamberlain & Johnson, 2003). In an effort to elucidate the sociocultural meaning of risk such theories also automatically criticise other approaches that present an unfavourable or problems-focused account. This has the potential, albeit inadvertently, to minimise the very real dangers individuals may experience as a direct result of their behaviours (Dwyer & Wyn, 2001).

Second, stigmatisation and blame, which are features of some theories of risk, as argued by Bessant (2000, 2002) and Lupton (1993) for example, are not necessarily inevitable outcomes of a risk discourse (Mallett et al., 2006). The majority of the social welfare and health programs in Australia implicitly utilise a risk framework to define those who access such services. Many of these programs and services however, focus on
promoting and developing personal resources, such as well-being, resiliency, and community engagement, to enable individuals accessing these services to lessen their engagement in risk practices. Moreover, these service models tend to emphasise and promote the right of the individual to receive assistance for problems that they may not be able to resolve through their own devices (Chamberlain & MacKenzie, 2004).

Finally, sociocultural perspectives operate at the level of grand theory and often provide little evidence to support their claims. As a result, they do not provide a concrete basis from which to assist those most in need or elucidate how their ideas can be translated into meaningful practice. Tackling structural issues, such as gender relations, ethnicity, poverty power structures, can seem an insurmountable task when the priority is on immediately assisting individuals in perceived need (Moore, 2002). Moreover, these perspectives often fail to elucidate an alternative vision capable of addressing the needs of people within the budgetary constraints that government departments and community organisations operate.

2.3. Young People as At-risk

The category of young people – like the idea of risk – is socially constructed and has varied over times, places and cultures. The discourse of risk that pervades late-modern Western societies, including Australia, is arguably central to the way young people are defined by governments, policy makers, service providers and the broader community more generally (Bessant et al., 1998; Mallett et al., 2006; Moore, 2002; Wyn & White, 1997). Young people are held to be inherently at-risk because of the transitional stage or phase of life they occupy – that is, they are in a state of becoming or growing up, of moving from being an immature child to being a mature adult. Furthermore, the at-risk label directs attention solely to the problems of and with young people as they make this transition (Bessant, 2002; Griffin, 1997; Kelly, 2003; Mallett et al., 2006; Rosenthal, 2004; Wyn & White, 1997).

During the supposed transition to adulthood, young people undergo a number of physical and psychological changes and complete a number of developmental tasks,
such as forming sexual identity, forming significant relationships with individuals external to the family of origin, making choices about career paths, loosening ties with the familial home and assuming responsibility for one’s own actions (Klein, 1990; Griffin, 1997; Moore, 2002; Rosenthal, 2004; Mallett et al., 2006). This model of development assumes that all young people share common experiences and characteristics and that all must and will go through the same transition, in the same way, in order to achieve the outcome of healthy normal adulthood (Mallett et al., 2006; Wyn & White, 1997). The transition is typically seen as a turbulent period, often characterised, particularly within the developmental psychology literature, by the analogy of “storm and stress” (e.g. Arnett, 1992, 1999). This analogy focuses on the problems young people experience, such as conflict with parents, mood disruption (depression and anxiety) and engaging in risk or reckless practices, as they negotiate the developmental tasks they are required to complete (Arnett, 1999). Young people are viewed as at-risk and vulnerable because they are in the process of acquiring, but do not yet have, the full physical, psychological, social and moral competencies that adults are supposed to possess (Bessant, 2000; Rosenthal, 2004).

The centrality of risk to modern understandings of the category of young people evolved from research in the 1920s and 1930s. This research began to emphasise the social component of the category and linked problems of and with young people (as well as other marginalised groups, such as prostitutes and alcoholics) to changes in the economic and social structures of the time (Moore, 2002; Wyn & White, 1997). In the 1950s the labels “troublesome” and “delinquent” were popular and focused on the specific problem behaviours in which young people engaged (Rosenthal, 2004; Wyn & White, 1997). The identification and associated commentary of the problems of young people was also coupled with an increase in the responsibility of institutions and agencies external to the family unit for monitoring and managing their lives, such as schools, social welfare services and juvenile justice systems. This led to some being identified and labelled as at-risk and in need of extra attention and protection (Wyn & White, 1997). These at-risk young people were seen to be jeopardising their future through present behaviours – a future that is meant to be both desired and desirable (Rosenthal, 2004). Where earlier accounts of the at-risk category were applied to
specific sub-groups of young people, more recently it has evolved to encompass all young people as potentially at-risk and in need surveillance and control.

The construction of young people as an at-risk population can be seen to serve a number of functions. First, it reflects a benevolent, humanistic intention. Young people, as a group, are seen to be in-danger because of the harmful, or potentially harmful, practices in which they sometimes engage. Second, it can serve an economic function by directing the limited resources of social services and government departments towards those perceived to be the most in-need (Withers & Batten, in Rosenthal, 2004). Third, it can be seen as part of a long history of anxiety and fear about social and economic change, whereby risk-taking practices are seen as a barometer of general moral decay within a society. Young people, in particular, are singled out for increased monitoring and regulation because they are easy targets due to their developmental position in relation to adults, that is, they have less autonomy over their own actions and situation (Bessant, 2001; Rosenthal, 2004; Wyn & White, 1997).

The dominance of a discourse of risk in defining and understanding young people has however, greatly limited our understanding of young people. It assumes that young people are a homogeneous population. This is despite the fact that only a small minority of young people engage in so-called risk behaviours, and, most importantly, ignores the personal, social and economic, political, and historical contexts in which these practices occur (Rosenthal, 2004; Wyn & White, 1997). The at-risk category also has the potential to stigmatise sub-groups of young people, such as those who experience homelessness or use illicit drugs, who are seen to be at even greater risk (Mallett, et al., 2006).

This account of risk also tends to assume that risk and risk-taking is inherently negative, should be avoided at all costs and that the consequences for young people are held somehow to be worse than for other groups. This view ignores that risk can be both a pleasurable experience and a key aspect of learning and development for some young people and, indeed, adults. Lupton and Tulloch (2002), for example, explored the views and experiences of voluntary risk taking among 74 people across the lifecycle living in
New South Wales, Australia. Three major discourses emerged. First, risk-taking was part of a process of continual self improvement. People felt that through taking risks they could extend themselves and learn about their personal resources and identity. In fact, it was seen as almost impossible to reach one’s full potential without taking some risks. Secondly, risk-taking was part of greater emotional engagement in life, whereby the action of taking a risk heightened the sense of living that could not have otherwise been achieved. Thirdly, engaging in risk was about being able to control the risk and, more importantly, their emotional and physiological responses to the risk.

This account of risk also tends to ignore that some young people do not frame their practices as risky or, if they do see particular practices as potentially carrying negative consequences, they do not necessarily frame them in the same way as researchers and policy makers. In particular, young peoples’ experiences and perceptions of risk and risk-practices are not always associated with a sense of blame or moral outrage, as can be implied in the scientific version of risk (Abel & Fitzgerald, 2006; Duff, 2003; Green, Mitchell & Bunton, 2000; Kelly, 2005; Lawy, 2002; Mitchell, Crawshaw, Bunton & Green, 2001). Consideration of these points is not to argue however, that risk-based accounts of young people are necessarily inaccurate, as clearly in some cases these accounts reflect the experiences of some young people. Rather, such accounts of risk present a single view of the ‘reality’ of young people and ignores or excludes other factors that influence these accounts (Rosenthal, 2004).

2.4. Hepatitis C Risk Practices among Young People who Experience Homelessness

Young people who experience homelessness are considered to be particularly at risk of contracting hepatitis C because of the practices in which they are said to engage (AIHW, 2003; Crane & Brannock, 1996; Ensign, 1998; Mallett et al., 2006; Myers et al., 2005). This research has primarily focused on practices relating to drug use (particularly injecting drug use) and sexual activity. Although this research has typically discussed the implications for HIV infection, it is relevant to hepatitis C infection, albeit to varying degrees. There has been very little research on other pathways of transmission for hepatitis C among young people who experience homelessness. The
majority of this research on hepatitis C risk practices among young people who experience homelessness was conducted in the United States but has significantly contributed to the understanding of these young people in Australia.

2.4.1. Drug Use Practices

Estimates from a large number of studies both national and international, principally the United States, in urban environments indicate that illicit drug use among young people who experience homelessness is almost 3-4 times more prevalent than among young people living at home (Bailey, Camlin & Ennett, 1998; Baron, 1999; Fors & Rojek, 1991). Furthermore, they are more likely to report use of all classes of substances compared with home-based young people (Baer et al., 2004; Clatts & Davis, 1999; Clements et al., 1997; Fors & Rojeck, 1991; de Man et al., 1993; Greene, Ennett & Ringwalt, 1997; Howard, 1995; Klee and Reid, 1998b; Koopman et al., 1994; Pinto et al., 1994; Mallett et al., 2006; Rosenthal et al., 1994). Although marijuana and alcohol tend to be the substances most commonly used, with the majority reporting recent use, substances, such as amphetamines, crack or cocaine, hallucinogens and ecstasy, are also frequently used (Rosenthal et al., in press; Klee & Reid, 1998a). The concurrent use of more than one substance or polydrug use is also very common among young people who experience homelessness (Booth & Zhang, 1997; Klee & Reid, 1998a; Mallett et al., 2003; Rosenthal et al., in press). Young people who have been homeless for longer periods of time are more likely to use most types of drugs (Greene et al., 1997; Rosenthal et al., in press).

While there is some evidence suggesting that the type of substance used is related to the hepatitis C transmission, of greater concern are injecting drug use practices. There has been a significant amount of research examining these practices among young people who experience homelessness, which indicates they are more likely to have ever and recently injected illicit drugs (Athey, 1991; Clatts & Davis, 1999; Howard, 1995; Johnson et al., 1996; Lheude & Moore, 1994; Goodman & Berecochea, 1994; Lifson & Halcón, 2004; Rosenthal et al., in press). A study of 843 young people who were currently homeless (aged 12-25 years) in Victoria and Queensland, Australia, recruited
through housing and health services found that 24% ever injected drugs (Hillier et al., 1999), which is substantially higher than in the general Australian population (AIHW, 2005). Among 14 to 19-years-olds among the general population, 1% are believed to have ever injected drugs, while among 20 to 29-years-olds the prevalence of having ever injected drugs was approximately 4% (AIHW, 2005). The prevalence reported in other studies conducted in Australia and other developed countries varies but all present a similar picture of engagement in injecting drugs.

Young people who experience homelessness are more likely than home-based peers to have shared a needle with another person while injecting on at least one occasion (Lheude & Moore, 1994; Mallett et al., 2003). Roy, Haley, Leclerc, Cedras and Boivin (2002), for example, in a survey of 980 street-based young people aged 14-25 years in Canada found that slightly over one-half had ever injected. A substantial minority (14%) had reported using an unclean needle or syringe the first time they had injected and a little over one-third (38%) had used unclean equipment. Surveys of recent injecting practices have also indicated high levels of sharing of needle and injecting equipment (Myers et al., 2005; Mallett et al., 2006). Clements et al. (1997), in a survey of street-based young people in the United States, found that two-thirds of those who had recently injected had also recently shared needles or syringes, while Rosenthal and colleagues (1994), in a small survey of young people who experience homelessness in Australia, found that approximately 60% of those who had injected reported they had shared needles. They also found that only one-third of young men and one-fifth of young women reported “usually” cleaning their shared needles. The duration of homelessness is also related to injecting drug use, with those who have been homeless for longer periods of time more likely to have injected drugs than those who have recently become homeless (Rosenthal et al., in press).

2.4.2. Sexual Practices

Although sexual practices are now considered to play a very small role, if at all, in the transmission of hepatitis C they are discussed here because it is still theoretically plausible (Dore et al., 1999; MacDonald & Wodak, 1999; Rosenblum et al., 2001;
The large number of studies that have documented the sexual practices of young people who experience homelessness indicate they are much more likely to be sexually active than home-based young people (Athey, 1991; Booth & Zhang, 1997; Clatts & Davis, 1999; Clements et al., 1997; Goodman & Bercoochea, 1994; Mallett et al., 2006; Taylor-Seehafer & Rew, 2000) and begin sexual relationships at a much earlier age – typically two years earlier or around the age of 12 or 13 years (Johnson et al., 1996; MacDonald et al., 1994; Taylor-Seehafer & Rew, 2000). Rosenthal and colleagues (1994) found that compared to home-based young people, those who were experiencing homelessness in Australia (15-18 years) were much more likely to have had oral, vaginal or anal sex with a casual or regular partner, as well as a greater number of sexual partners in the previous six months. The young people who experienced homelessness were also much more likely to have engaged in sexual practices deemed high-risk, for example inconsistent use of condoms during sex, with both casual and regular partners.

A high number of partners, both recent and historical, and infrequent condom use, particularly with casual partners, are common findings among studies with young people who experience homelessness in the United States (Clatts & Davis, 1999; Clements et al., 1997; Forst, 1994; Greenblatt & Robertson, 1993; Johnson et al., 1996; Lheude & Moore, 1994; MacDonald et al., 1994; Rew et al., 2002). De Rosa et al. (2001) for example in a study of HIV risk practices and testing among young people who experience homelessness in California report that 61% were sexually active in the past month. A large number of the young people (41%) who were sexually active during this period had more than two partners. Moreover, 53% reported inconsistent condom use, which the authors defined as having not used a condom during their last sexual encounter or only generally “sometimes” or less frequently using condoms during oral, vaginal and anal sex.

Several studies have noted that young people who experience homelessness are significantly more likely to have ever or to currently engage in survival sex than home-based young people. Survival sex refers to having or trading sex to meet subsistence needs, such as food, money, shelter or drugs (Johnson et al., 1996; Forst, 1994; Greene,
Ennett & Ringwalt, 1999; Greenblatt & Robertson, 1993; Rossiter et al., 2003). Survival sex is an important distinction to other sexual practices in the possible risk for hepatitis C, as it presents the potential for sexual encounters where the young person has less control over the decision to use condoms. Moreover, there is a strong association between engagement in survival sex and other practices deemed high risk, for example illicit drug use (Greene et al., 1999).

2.4.3. Other Factors Associated with Hepatitis C Infection

There has been very little research undertaken among young people who experience homelessness concerning other correlates of hepatitis C infection. This small body of research has reported on prison contact, tattooing and skin piercing, and household contact.

A small number of studies have noted that young people who experience homelessness in Australia, Brazil, and the United States are more likely to spend time in prison or juvenile justice detention (Inciardi & Surratt, 1998; Milburn, Rotheram-Borus, Rice, Mallett & Rosenthal, 2006; Mallett et al., 2006). For example, Milburn, Rotheram-Borus and colleagues (2006) in a comparative study of young people who experience homelessness in Australia and the United States report that 5% of young people surveyed in Australia have a history of juvenile detention or gaol, while 16% had in the United States. Considerably more research, particularly from the United States, has been undertaken on young people’s engagement in activity that may lead to imprisonment or detention. This research suggests that young people who experience homelessness are more likely than home-based young people to engage in practices, such as assault, theft, robbery and selling drugs (Baron & Hartnagel, 1998; de Man et al., 1993; Hagan & McCarthy, 1997; Kipke, Simon et al., 1997; Tyler & Johnson, 2004; Whitbeck & Simons, 1993).

Together these relatively small bodies of research indicate that young people who experience homelessness are more likely to spend time in prison and/or engage in practices that can lead to time in prison. As discussed in Section 1.1.5.3., contact with a
prison system is believed to be associated with higher rates of hepatitis C infection due to unsafe injecting drug use and tattooing practices while incarcerated. This is particularly relevant to young people who experience homelessness, given they are held to be much more likely than home-based young people to inject illicit drugs (Athey, 1991; Clatts & Davis, 1999; Howard, 1995; Johnson et al., 1996; Rosenthal et al., in press; Roy et al., 2001) and those who inject illicit drugs outside prison are likely to continue doing so once in prison (Hellard et al., 2004).

There have also been relatively few studies documenting other practices relating to hepatitis C transmission, such as non-injecting forms of skin penetration (e.g. tattooing and body or skin piercing) and exposure to another’s blood through household contact, among young people who experience homelessness. One study was with an Australian cohort as part of a pilot hepatitis C education and prevention program for young people who experience homelessness. Myers et al. (2005) surveyed 105 young people (aged 15-25 years) who accessed an outreach bus at several sites in metropolitan Melbourne. Although only 50% of these young people were currently homeless and results were not tabulated by this factor, they found that a substantial minority had potentially been exposed to another’s blood through mechanisms other than those relating to drug use. Approximately 13.5% had come into contact with someone else’s blood in the past three months, 10% had been pierced or tattooed by someone who was not a professional practitioner, 10% had used another razor and 9% had used another’s toothbrush. Furthermore, young people aged 15-19 years were less likely than those aged 20-25 years to have come into contact with someone else’s blood or have used someone else’s razor or toothbrush.

Other studies examining such practices among young people who experience homelessness typically only report data on the prevalence of potentially unsafe tattooing and piercing (Lifson & Halcón, 2001; Roy et al., 2001). Roy et al (2001) in a survey of street-based young people experiencing homelessness in Montreal, Canada, found that 37% had a tattoo, a further 19% had been tattooed by a non-professional and 78% have a skin piercing. Lifson and Halcón (2001), on the other hand, indicate that 20% of a sample of young people experiencing homelessness in Minneapolis, United States, they
surveyed had been tattooed using an unsterilised needle or that had been used by another person, while 18% had received a skin piercing under similar conditions.

2.4.4. Limitations of Research on Young People who Experience Homelessness

The evidence that appears to support the idea that young people who experience homeless are an at-risk population, while compelling on one level, is heavily driven by the manner in which the research was undertaken. In particular, this includes the exclusion of the social context of risk practices related to the transmission of hepatitis C, particularly illicit drug use, and the ways in which samples have been defined. These issues are discussed below.

2.4.4.1. Social Context of Illicit Drug Use Practices

Much of the research examining young people who experience homelessness is informed by a positivist account of risk which can frame these young people as a homogeneous at-risk population. Recent research has highlighted the diversity of illicit drug use experiences within this population (Keys et al., 2006; Mallett et al., 2006) and argues that such risk-based accounts do not account or describe the majority of young people who experience homelessness. In particular, it ignores the social contexts in which some of these practices occur. Keys and colleagues (2006), for example, examined the trajectory of drug use and related problems over time among 40 young people who experienced homelessness. They found that almost all who had identified their drug use as problematic when first interviewed had, by the completion of the two-year study, either reduced their drug use or ceased using drugs altogether. Interestingly, most had done so without the aid of treatment programs or related services. These changes were often associated with having a supportive partner, improved relationship with their parent(s), who they were living with and where, and securing stable accommodation. Although the findings at the beginning of their research – that many had engaged in drug use – neatly fits within the vast body of at-risk literature, their
longitudinal data portrays a much different and more positive story, which is rarely captured or even contemplated in the catalogue of risk.

Of greater relevance to the transmission of hepatitis, is a complementary body of emerging research that indicates that people’s participation in injecting drug use practices is heavily influenced by the social, cultural, spatial, geographic and political environments or contexts in which they exist (Bourgois et al., 2004; Crofts et al., 1996; Dovey, Fitzgerald & Choi, 2001; Garfein et al., 2004; Habib, 2003; Higgs et al., 2001; Kerr, Kimber & Rhodes, 2007; Moore & Dietze, 2005; Reid et al., 2002; Rhodes, Davis & Judd, 2004; Rhodes et al., 2003; Rhodes, Singer, Bourgois, Freidman & Strathdee, 2005).

Within this literature, for example, is noted that injecting drug use is rarely a solitary event and that the sharing needles, syringes and other injecting equipment typically occurs within the confines of close personal relationships (Bourgois et al., 2004; Crofts et al., 1996; Habib, 2003; Hahn et al., 2002; Montgomery et al., 2002; Vidal-Trecan, Varescon-Pousson & Boissannas, 2002). In a study of the circumstances surrounding the initiation of injecting drug use among 300 young people aged 17-25 years in Australia, it was observed that the first occasion of injecting drugs was often an unplanned event but generally their own idea (or at least not someone else’s idea). Young people were often injected by another person, most commonly a sexual partner, friend or acquaintance, which was also strongly influenced by gender relations. Young women were typically injected by a partner, while young men were typically injected by a friend or acquaintance. The most common reasons for the first injection were desire to experience the rush or curiosity (Crofts et al., 1996; Fitzgerald, Louie, Rosenthal & Crofts, 1999). Similar findings have been noted among Canadian young people living on the street (Roy et al., 2002).

The importance of the social context of injecting has also been noted for occasions after the first time. Habib (2003) in a study of injecting drug users in Australian found that needle sharing practices were primarily associated with long-standing relationships, particularly sexual ones. He also found however, that sharing was associated with the
level of drug dependency, misconceptions about hepatitis C transmission, and logistical factors, such as poor access to injecting equipment, limited hours of operation of NSP and pharmacies, and fear of police.

Further evidence for the role sexual relationships can play in mediating young people’s engagement in unsafe injecting practices is provided by a large research program undertaken in San Francisco, United States, between 1997 and 2004 (Bourgois et al., 2004; Center for AIDS Prevention Studies, 2007; Hahn et al., 2002). This program (known as ‘the UFO study’) extensively examined hepatitis B, hepatitis C and HIV infection among young injecting drug users. The investigators report that in addition to more frequently cited predictors of hepatitis C infection, such as duration of injecting drug use and reusing other’s needles to inject drugs, being initiated into injecting drugs by a sexual partner and being injected by someone else in the past month was significantly associated with hepatitis C infection (Hahn et al., 2001). On closer examination of injecting practices, they found that young women were significantly more likely than young men to share needles (and equipment) with a sexual partner (72% vs. 43%, respectively) and be injected by their sexual partner (32% vs. 16%, respectively; Evans, et al., 2003).

In collaboration with the UFO study, Bourgois et al. (2004) conducted ethnographic research to examine why young street injecting drug users engaged in practices likely to transmit hepatitis C and other blood-borne viruses and, in particular, to shed further light on the associations between gender and such practices. They found that everyday violence was an overwhelming factor in explaining young women’s engagement in unsafe injecting practices. They found that many of the young women interviewed had entered into abusive, controlling and exploitative relationships with older men who injected drugs shortly after entering the street drug scene. This type of relationship had largely become normalised for many young women and was linked to a perceived need for protection while on the street, a sense of worth and ideas of romantic love. Within this context, young women had little control over the way they engaged in injecting drug use and, consequently, were at considerable risk of contracting hepatitis C (and other blood borne viruses).
Although by no means an exhaustive review of the social context of illicit drug use, these findings illustrate the importance of examining the contexts in which putative risk practices occur. These observations are particularly important for hepatitis C prevention measures, as they show that engaging in such practices is more than simply disregarding knowledge of the consequences of such actions but are subject to a variety of social contexts and processes, such as friendships and sexual relationships (Bourgois et al. 2004; Crofts et al., 1996; Habib, 2003). If significant inroads are to be made on the hepatitis C epidemic then addressing these factors is of prime importance. It may also go someway to explaining why behavioural and knowledge based prevention programs have little to no long term success.

2.4.4.2. Sampling and Recruitment Limitations

The current body of research on hepatitis C risk practices among young people who experience homelessness is also limited by the manner in which the research has been undertaken, in particular, the way in which samples are defined and recruited. The majority of studies on young people who experience homelessness, particularly in the United States, have exclusively recruited from street sites or crisis accommodation. Young people from these sites are however, thought not to reflect the experiences of other young people who experience homelessness, such as those living with friends, partners or relatives, who do not have contact with street environments or primary homelessness services and who are likely to represent the majority of young people who experience homelessness (Chamberlain & MacKenzie, 1998; Myers, Mallett, Rossiter & Rosenthal, 2003).

A related issue also is that the majority of these studies have focused on young people with extensive histories of homelessness. These young people, who represent a minority of young people experiencing homelessness, tend to be in a more disadvantaged position and more likely to engage in potentially health compromising practices than those who have only recently become homeless (Greene et al., 1997; Mallett et al., 2006; Milburn et al., 2005; Rosenthal et al., in press; Solorio, Milburn, Rotheram-
Borus, Higgins & Gelberg, 2006). In a comparison of recent and longer-term homeless young people (aged 12-20 years) in Australia and the United States, Milburn, Rotheram-Borus et al. (2006) report that those who were homeless for longer periods of time tended to be in a more disadvantaged position and more likely to engage in practices that potentially compromise their health, such as using all classes of illicit drugs, injecting drug use and unsafe sex. After controlling for all other factors however, young people who had recently become homeless tended to be younger than longer-term homeless and less likely to be pregnant, have histories involving contact with child protection agencies, engage in sex work, have less than four lifetime sexual partners, and require help for general health issues. They were however, more likely to currently be in education, require help for school-related problems, have a higher unmet service need, and come from single parent families. Other studies have noted that longer-term homeless young people are more likely to report hepatitis C infection (Martins et al., 1995; Nyamathi et al., 2002; Rosenthal et al., 2003) and poorer physical health (Ensign, 1998; Klee & Reid, 1998a).

These issues relating to the definition and sampling of young people who experience homelessness have lead to an understanding based solely on one aspect of homelessness – a potential more extreme and chronic aspect – and does not account for the diversity of experiences of the larger population. In particular, focusing primarily on young people currently living on the street or in crisis accommodation and those who have been homeless for extended periods of time is likely to inflate the prevalence or perceived importance of potentially health compromising practices relating to hepatitis C among these young people. Moreover, it is also likely to confound the relationship between these practises, the experience of homelessness and the practice of hepatitis C testing. It is within this context that the research for this thesis preceded. The remainder of this chapter outlines the principle aims of this thesis, how these aims are operationalised into research question, and the methods employed to answer these questions.
2.5. This Thesis

Despite the large number of tests performed each year and the effort expended in developing policy surrounding testing, very little research has been undertaken examining the human factors associated with hepatitis C testing (Loxley et al., 2000), in particular, who is tested for hepatitis C and what are their reasons or motivations for undertaking testing. Understanding these issues is vital to developing strategies aimed at preventing the spread of hepatitis C, as many of those infected with hepatitis C are believed to be unaware of their status (Dore et al., 1999; Gordon, 1999; Rhodes et al., 2001). Furthermore, understanding these issues would provide valuable information for testing policies and services offering testing, as it provides insight into concordance or discordance between the intended targets of testing and their motivations and those who are actually tested for hepatitis C. Such findings can also enable the development of more tailored approaches to testing and more positive experiences and outcomes for testing recipients and broader public health concerns, such as the prevention of hepatitis C transmission in the community (Loxley et al., 2000).

The broad aim of the research presented in this thesis is to examine the human factors associated with hepatitis C testing among young people who experience homelessness in Melbourne. This broad objective is articulated through two specific aims: 1) to examine patterns of hepatitis C testing among young people who experience homelessness in Melbourne and how they relate to behavioural and contextual factors, and 2) to examine the social, behavioural, psychological and environmental context in which hepatitis C testing occurs for these young people. In addressing these aims this thesis also broadens the focus of research on hepatitis C testing and young people who experience homelessness beyond the typical risk-based discourse that has dominated these fields. In particular, this research recruited young people who have recently become homelessness for the first time and recruit young people from a broad range of services. To address these equally important aims two studies were undertaken: 1) longitudinal panel surveys, and 2) semi-structured interviews.
2.5.1. Study 1: Longitudinal Panel Surveys

The first study presented in this thesis examined patterns of hepatitis C testing among young people who experience homelessness in Melbourne and how they relate to behavioural and contextual factors. In particular, this study determined the prevalence and incidence of testing and identified the characteristics of those tested. This study employed a longitudinal panel survey design to address these questions.

The limited body of literature on hepatitis C testing, and indeed the larger body of research on young people who experience homelessness, has entirely been cross-sectional in design and has typically limited survey items to measures of blood-borne virus risk, a small number of variables relating to service utilisation (for other blood-borne viruses) and demographic characteristics. This study sought to overcome these limitations and extend the current literature by employing a longitudinal design and utilising a large number of social, behavioural and contextual factors in order to widen the understanding, beyond a risk practice understanding, of this important issue.

2.5.2. Study 2: Semi-structured Interviews

The second study presented in this thesis examined the social, behavioural, psychological and environmental context in which young people who experience homelessness in Melbourne are tested for hepatitis C. In particular, this study sought to answer the questions, why are young people who experience homelessness tested for hepatitis C and what is the relationship between their reasons and their experience of homelessness, their gender and the way they manage their health more generally. This study employed a semi-structured qualitative interview design to answer these questions. It also utilised a sub-sample of young people who participated in the first study.

Qualitative methodology was chosen for the study because it provides a clear and effective means of gathering a rich body of material from which to examine the reasons...
young people who experience homelessness undertake testing for hepatitis C and, importantly, the meaning behind these reasons. Moreover, this methodology allows for testing to be examined from the experience of the young people themselves (Chamberlain et al., 1997; Hathaway, 1995). One of the major limitations to the current understanding of hepatitis C infection and testing is that the majority of the research to date has used quantitative methods. These methods are inadequate to answer the questions posed in this study because they have limited capacity to examine or account for the social, historical and cultural contexts within which hepatitis C testing occurs and tend to simplify phenomena in an effort to provide empirical measurement and generalisability of findings (May, 2001; Lupton, 1999a). Qualitative methods, on the other hand, enabled this study to achieve these aims and allow young people the opportunity to recount their story using their own words and indicate what they felt is important, without prescribing what they are asked and how they should respond (Keogh, 2003).

2.5.3. Project i: Homeless Young People in Melbourne and Los Angeles

The longitudinal survey data used in the first study and cohort of recently homeless young people from which participants were recruited into the second study are from an existing research program: Project i: Homeless Young People in Melbourne and Los Angeles. As stated in the preface, the research questions and data analyses performed in Study 1, and the research questions, recruitment of young people, collection and analysis of interview material in Study 2, represent original work towards the thesis.

Project i, was a longitudinal study of young people who experienced homelessness in Melbourne and Los Angeles. It was undertaken over a five year period (2000-2005) and was a collaborative study undertaken by researchers at the Key Centre for Women’s Health in Society, School of Population Health, The University of Melbourne and the Center for Community Health at the University of California, Los Angeles. The

11 The study was formerly located at the Australian Research Centre in Sex, Health and Society, Latrobe University
research program comprised three areas: surveys and interviews with young people who were experiencing homelessness, surveys and interviews with service providers; and reviews of Local, State and Federal Government policies relating to homelessness. As this thesis draws only on the Australian component of Project i, only research undertaken in this country is described in greater detail.

The research with young people involved recruiting two cohorts: 165 recently homeless and 509 experienced (or long-term) homeless (see Mallett et al., 2003). The experienced homeless young people participated in a single baseline survey, while the newly homeless young people completed six surveys over two years (baseline, 3-, 6-, 12-, 18-, and 24-month follow-up). The surveys questioned young people extensively about their family background, living arrangements, reasons for leaving and returning home (the latter in follow-up surveys only, if applicable), drug use practices, sexual practices, blood-borne virus risk, health (physical, mental and sexual) issues and management, social connection and support, employment and education, and service utilisation. Semi-structured interviews were also undertaken with 40 young people in newly homeless cohort approximately 18-months after their baseline survey. These young people were further questioned about their living arrangements history, social support, drug use and sexual practices, education and subsistence strategies, health issues and how their experience of homelessness had impacted on their lives.

The research with service providers in Australia involved surveys with 150 service providers (see Mallett, Rosenthal & Myers, 2001; Myers, Rossiter & Rosenthal, 2002; Rossiter, Myers, Mallett, Edwards & Rosenthal, 2001) and 34 semi-structured qualitative interviews with service providers from a range of sectors including housing, mental health, juvenile justice, homelessness prevention and Centrelink12 (see Mallett et al., 2003).

12 Centrelink is the organisation responsible for administering social welfare payment to Australian Citizens.
Chapter 3

Rates and Correlates of Hepatitis C Testing

3.1. Overview

Current hepatitis C testing policies in Australia (e.g. ANCAHRD, 2003), and indeed many in other developed countries (e.g. CDC, 1998, 2001a; DH, 2004), direct testing towards those who have a risk factor, according to current epidemiological and medical evidence about the transmission of hepatitis C. However, very little research has been undertaken examining the correlates of hepatitis C testing and it is not reliably known whether the actual recipients of testing reflect the intention of policy. Understanding this question is an important public health issue, as it can lead to the development of more tailored approaches to testing, and hopefully more positive experiences and outcomes for testing recipients (Loxley et al., 2000). It provides a means of accessing whether current public health policies and programs are having the desired effect or whether the increase in the annual incidence of testing over the past decade is, in fact, associated with the widespread undertake of testing among so-called low risk individuals. This concern is of particular importance, given the costs associated with serology testing and the stress of having a test on the testee.

The most consistent findings to emerge from the very small body of research examining hepatitis C testing suggests that those who engage in so-called risk practices, particularly injecting drug use, those with better knowledge of hepatitis C, and those who have contact with services because of other blood-borne viruses are more likely to have been tested for hepatitis C. Given the paucity of research conducted and a number of methodological limitations, the reliability, validity and generalisability of these findings are limited. One limitation of the very small body of knowledge on hepatitis C testing is that previous studies have entirely been cross-sectional in design. Although such designs have many strengths, they are limited to examining practices which have already occurred and the correlations with these practices. Longitudinal designs, on the other hand, provide a means of assessing change over time or the incidence of new
cases of testing as they occur. A further limitation to the current understanding of the correlates of hepatitis C testing is that it has been investigated using a small number of covariates, the majority of which have been epidemiological risk factors for hepatitis C infection. Social or contextual measures have generally been excluded or ignored. Although this can be justified, given the direct link between transmission and these practices, the sole use of these measures has limited the possible understanding of testing. Social or contextual measures however, may provide valuable insight into the characteristics of those who are tested for hepatitis C.

The study presented in this chapter aims to answer two specific questions relating to hepatitis C testing: 1) what is the prevalence of hepatitis C testing among young people who experience homelessness in Melbourne and how is it related to behavioural and contextual factors; and 2) what is the incidence of new cases of hepatitis C testing and how is it related to behavioural and contextual factors. In answering these questions, this study aims to overcome some of the limitation of previous research and extend the current knowledge of the correlates of hepatitis C testing. In particular, a longitudinal design is employed to examine changes over time and the incidence of new cases of testing as they occur. A cohort of young people who have recently become homeless for the first time were recruited from services for young people and the homeless across Melbourne and surveyed on three occasions over two years.

This study also utilises a large number of social, behavioural and contextual factors in order to widen the understanding, beyond a solely epidemiological risk framework, of this important issue. The specific factors that are used can be grouped into four categories: socio-demographic and living arrangements, risk practices (including drug use practices, sexual practices, blood-borne virus risk), health (physical, mental and sexual), and service utilisation. The specific variables within each of these categories were selected on the basis of previous research on hepatitis C infection and testing or informed speculation.
3.1.1. Socio-demographic and Living Arrangements

Age and gender are used because national surveillance data indicates that infection rates vary by these factors (NCHECR, 2005). Moreover, one study reported different rates of hepatitis C testing by age group (Myers et al., 2005). Sexual identity was used because there is some evidence that young people who identify as gay, lesbian, bisexual or are unsure about their sexual identity are more likely than heterosexual young people to engage in practices that can lead to the transmission of hepatitis C, such as injecting drug use (Smith, Lindsay & Rosenthal, 1999).

Participation in education was used because it may lead to increased hepatitis C knowledge (i.e. through health education) and, possibly, increase the likelihood of testing as noted in one study (Van de Ven et al., 1999). Although hepatitis C knowledge among high school students in Australia is typically poor (Lindsay, Smith & Rosenthal, 1999; Smith, Agius, Dyson, Mitchell & Pitts, 2003), it is likely to be better than those not in education. On the other hand, participation in education may lessen the likelihood of engaging in potentially health compromising practices and, perhaps, reduce the likelihood or need for testing because it provides young people with an implicit level of support through school welfare officers, nurses and teachers.

The economic position of young people may be associated with the likelihood of engaging in practices that are potentially health compromising and in turn the need for contact with social and health services for assistance, and therefore testing for hepatitis C. Unemployment and poverty has been linked to the use of illicit drugs, either as a catalyst for drug use or as a consequence of drug use (Bousman et al., 2005; Fergusson, Horwood & Woodward, 2001; Mallett et al., 2003; Spooner & Hall, 2002). The association between economic position and drug use has been noted in many studies (Loxley et al., 2000; Myers et al., 2005). Engaging in survival sex may be related to hepatitis C testing. There is some evidence of an association between HIV testing and survival sex (de Rosa et al., 2001). Furthermore, participation in the regulated sex industry in Victoria requires regular health screening as part of accreditation (Prostitution Control Act 1994). Although the focus of the health checks is HIV and
sexually transmitted infections, Section 20.2.a.i. of the Act states that “regular blood
tests, on at least a quarterly basis for HIV and each other sexually transmitted disease
for which blood tests are appropriate” are required, which may include hepatitis C.

The recent living arrangements of young people, such as a parent’s home, a friend’s
house, juvenile detention centre or jail, or the street, squat or abandoned building are
used in this study as a measure of homelessness. The specific types of living
arrangements are preferred over a single measure of homelessness, as different living
arrangements may reflect different life circumstances of young people, which provide
different opportunities for testing. Young people, for example, are routinely screened
when entering prison or detention, while young people living in State-provided crisis
accommodation often have access to testing via visiting health practitioners.

3.1.2. Risk Practices

A range of risk factors for hepatitis C are examined because there is evidence, albeit to
varying degrees, that they are related to the transmission of hepatitis C or testing for
hepatitis C or HIV. Injecting drug use was chosen because it is the primary mode of
transmission for hepatitis C infection in Australia (Dore et al., 1999) and is often linked
to testing (Watson et al., 1999; Van de Ven et al., 1999). Use of specific types of drugs
is also examined because several have been found to be related to hepatitis C infection.
The specific drugs that have been implicated include opiate-based substances (injecting)
and cocaine (injecting and inhalation) (Greenfield et al., 1992; Hocking et al., 2001;
Koblin et al., 2003; MacDonald et al., 2001). Other types of drugs for which there is no
current evidence are also included because they have not been extensively examined
and/or can be consumed in a manner (i.e. injecting or inhalation) in which hepatitis C
transmission is plausible. Sexual practices are used because it is theoretically plausible
that sexual contact is a mode of transmission (Dore et al., 1999; MacDonald & Wodak,
1999; Rosenblum et al., 2001; Thorpe et al., 2000) and may be a reason for being tested.
Moreover, separate measures for consensual and involuntary sex are specified as they
reflect situations where the perceived chance for infection and the desire or need for
testing is likely to differ.
A number of standardised measures of blood-borne virus risk, such as sharing injecting equipment, skin piercing and tattooing and sharing personal hygiene equipment, are also used because of the direct link to the transmission of hepatitis C (Crofts, 2001; Dore et al., 1999; Farrell et al., 1993; Fry & Lintzeris, 2003).

3.1.3. Health

A variety of measures of physical, mental, sexual and reproductive health are used in this study. Perceived physical health, particularly poor health, may lead a young person to be tested for hepatitis C. This may occur because young people link the physical symptoms of illness to hepatitis C or because an independent health issue causes them to have contact with a health service. One study observed a link between having a medical condition and hepatitis C testing (Goldberg et al., 2005). Measures of mental health are used because they provide insight into the state of mind of young people at the time of testing. Suicide and self-harm are also included, as they measure specific aspects of mental health.

Testing for other infections, in particular HIV and other STIs, may also be related to hepatitis C testing. One study has observed that hepatitis C is often undertaken as part of a battery of tests, which also includes HIV (Loxley et al., 2000). Although this study did not examine STI testing, service providers consulted for this research indicted that testing for sexually transmitted infections may also have been included in the range of tests young people received.

Pregnancy (or having a baby) is examined because women are offered testing as part of antenatal care (DHA, 2005). Furthermore, young women who become pregnant and young men whose partner has become pregnant are obviously engaging in unprotected sex, which may be a reason for being tested.
3.1.4. Service Utilisation

A crucial aspect of being tested for hepatitis C is help-seeking and the use of services. This is measured in three ways: seeking help for specific issues, such as housing, drug and alcohol use, school problems and general health problems, accessing specific types of services (hospitals, needle and syringe exchange programs, drug and alcohol treatment programs, and detoxification), and case management. Seeking help for an issue or accessing specific services indicates a young person has a perceived need, which may be more important in understanding hepatitis C testing than solely engaging in a practice or displaying a particular characteristic. These measures also provide insight into the sites of testing or indicate possible pathways to testing, if a service site is not directly involved in testing. Many services that young people who experience homelessness access in Melbourne provide assistance for multiple needs and frequently refer young people to more appropriate services when needed (Myers et al., 2002).

Case management and having a case plan represent a particular form of service provision, whereby young people have one person who is responsible for coordinating the different services they receive. Young people’s access to services may be more coordinated and targeted than those who do not have one. These variables were used because they can provide insight into whether it is the individualised coordination of contact with services that is important to being testing for hepatitis C, rather than a specific need or practice.

3.2. Method

3.2.1. Participants

The participants for this study were 165 (88 female, 77 male) young people who had recently become homeless for the first time and who were residing in metropolitan Melbourne, Australia, at the time they were recruited. Young people were recruited from 48 community services that target young people or the homeless over a 20-month period beginning October 2000 and ending June 2002. Young people were eligible to
participate if they were: 1) aged 12-20 years, 2) had spent the last two consecutive nights away from home (either without their parent’s or guardian’s permission, if under 17, or had been told to leave), and 3) had been living away from their parent(s) or guardian(s) for less than six months. The average age of participants, when first surveyed, was 17.0 years (SD = 1.43) and ranged from 12 to 20 years. The majority of eligible young people were referred from refuges or information and referral services (see Table 1). All regions of Melbourne were represented, although the Western region of Melbourne was the least represented (see Table 2).

Table 1. Number of young people recruited by service type

<table>
<thead>
<tr>
<th>Service type</th>
<th>Number of young people</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>General information and referral</td>
<td>39</td>
<td>23.6</td>
</tr>
<tr>
<td>Housing information and referral</td>
<td>50</td>
<td>30.3</td>
</tr>
<tr>
<td>Income support</td>
<td>15</td>
<td>9.1</td>
</tr>
<tr>
<td>Refuges/accommodation</td>
<td>50</td>
<td>30.3</td>
</tr>
<tr>
<td>Other service types</td>
<td>11</td>
<td>6.7</td>
</tr>
</tbody>
</table>

Table 2. Number of young people recruited by metropolitan region

<table>
<thead>
<tr>
<th>Region</th>
<th>Number of young people</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Northern</td>
<td>35</td>
<td>21.2</td>
</tr>
<tr>
<td>Southern</td>
<td>38</td>
<td>23.0</td>
</tr>
<tr>
<td>Eastern</td>
<td>40</td>
<td>24.2</td>
</tr>
<tr>
<td>Western</td>
<td>21</td>
<td>12.7</td>
</tr>
<tr>
<td>Inner City</td>
<td>31</td>
<td>18.8</td>
</tr>
</tbody>
</table>

3.2.2. Design

A longitudinal panel survey design was employed. A cohort of young people who had recently become homeless for the first time was surveyed on three occasions over two
years using a large number of standardised items and measures. Young people were survey ed at baseline and at twelve and twenty-four months after baseline.

The decision to not use all of the survey waves collected by Project i was made for two reasons. First, individual surveys within each survey wave were not undertaken precisely when they were scheduled. A window in which the surveys could be undertaken was defined to allow for the difficulty in maintaining contact with young people who experience homelessness. The window was defined as one month before the survey was due to be conducted and one month before the next survey wave was due to begin. Only approximately one-third of interviews (32%) were completed one week before or one week after the due date. Surveys were completed across the full range of the window. Due to the pragmatic decision to enable participant retention however, the variable completion date of surveys meant that a single event (e.g. being tested for hepatitis C or engaging in drug use) potentially could be recorded on two survey waves. Using all the survey waves available would not provide a clean measure of the outcome and covariates, which could significantly overestimate the prevalence of hepatitis C testing and the importance of covariates. Second, not all measures were available at all the survey waves. The decision to use only three survey waves was a balance between using as many waves as possible and including as many items in statistical analyses as possible.

The specific survey waves used were chosen because of the even amount of time between survey waves, that is, they were 12-months apart, were not contaminated by responses potentially recorded on other surveys, and were waves in which the survey items of interest (discussed within the measures subsection) were available. An increase in the number of surveys waves would have greatly reduced the number of usable measures, which was contrary to one of the objectives of this study – to include a broad range of social and behavioural variables.
3.2.3. Procedure

3.2.3.1. Sampling and Recruiting

The young people who had recently become homeless for the first time were recruited directly from community services that target young people and the homeless across metropolitan Melbourne. These services were identified through a variety of resource, local government, and community guides (e.g. Bathgate, 2000; Lifeline Melbourne, 2000; Whitehorse City Council, 1999). Community services were selected as potential recruitment sites if they had contact with young people who experience homelessness as all or part of their work and were within 30km of the central business district. This distance was chosen because it ensured that the majority of Melbourne was represented but that it was still logistically possible to undertake recruitment within the resources of the study. In total, 109 community services were identified as potential recruitment sites and included refuges; housing services; information and referral services; health-related services; employment, education and training service; government assistance services; and prevention or intervention services.

The manager of each service was approached to seek the service’s participation as a recruitment site. Managers were briefed on the nature of the study and what would be involved in being a recruitment site. Only two services (0.2%) declined to participate, both citing insufficient time to refer young people. Upon agreeing to participate, services were given an information session that focused on the purpose of the project and participant eligibility criteria. Posters and flyers were displayed and placed throughout the service in visible areas. The advertisements asked young people between the ages of 12 and 20 years if they were currently living out of home and would like to participate in a research project, for which they would be paid $20. The advertisement also displayed a free-call number that potential participants could call to find out if they were eligible. Staff working at services also approached young people who they believed may be eligible and briefly outlined the nature of the project. If a young person expressed an interest in participating, the staff member would either give the young person the project’s free-call number and flyer or phone the free-call number on their behalf.
Research staff operating the free-call number established whether the young person met the entry criteria by asking key criteria questions, such as the young person’s age, where they were currently living and how long they had been living there. If they appeared to be eligible, a survey was scheduled at a mutually convenient time within the next few days. No data was collected on the number of ineligible young people who contacted the free-call number.

Forty-eight (45.0%) services referred eligible young people to the study. The average number of eligible recently homeless referred by a service was 3.2 (SD = 4.0) and ranged from 1 to 24 young people. This seemingly low percentage is due to the fact that the majority of young people (76.2%, see Mallett et al., 2006 & Rossiter et al., 2003) referred by services had been homeless for longer than six months and were not the focus of this study.

3.2.3.2. Conducting Surveys

All surveys were conducted by trained interviewers who had received approximately 40 hours of training. The training was conducted over five days and included lectures, role-playing, mock surveys, ethics training, emergency procedures and technical training.

Prior to commencing the baseline survey, interviewers conducted comprehensive eligibly screening using a 13-item screening instrument. The screening instrument was designed, among other objectives, to confirm eligibility, establish whether a young person had recently become homeless for the first time and to mask the eligibility criteria. If a young person was eligible, they were invited to participate in the survey proper and informed consent was then obtained (see Appendix A). As part of the informed consent process, young people were informed that interviewers were required to report current physical or sexual abuse (if the participant was under 17 years of age) and serious suicidal or homicidal feelings. If they were ineligible they were thanked for their time and given $5 compensation. No young people were deemed ineligible at this stage.
Surveys were undertaken in the form of an interview using computer assisted self interview (CASI) software (Questionnaire Development System, 1998) on IBM-compatible laptop computers. The majority of items were administered by the interviewer who read aloud the items and responses from the screen of the laptop and entered the participant’s response on their behalf. Questions regarding drug and alcohol use, sexual practices, and blood-borne virus risk, however, were administered using Audio-CASI, whereby, the participant wore headphones and listened to a computer-generated voice read aloud the items and responses. The participants also received visual prompts on how to respond to each item. These questions were administered in this format to increase the perceived privacy and, potentially, the reliability of responses. Prior to beginning this section of the survey, the interviewer provided instructions on how to use the computer and software. The interviewer remained in the room while the participant undertook the questions, although in a position where (s)he was unable to see the participant’s responses.

Once the baseline survey had been completed young people were asked to complete a “locator log” to facilitate the longitudinal component of the study. The locator log was a detailed record of personal contact information and included the young person’s current address, telephone number(s), email address, work details and the contact details of people they may have contact, such as parents, other relatives, friends, service workers, and other significant people. The locator log was routinely updated at the end of each follow-up survey and on any other occasion interviewers had contact with participants. The interviewers maintained regular contact with young people between surveys through mail, email and telephone correspondence. Correspondence included event cards (birthday, Christmas, etc.), reminders of forthcoming surveys, details about the Project’s website, and a quarterly newsletter for young people providing a project update.

The majority of baseline surveys occurred at the referral service, although some were conducted at the research centre from which this study was based. Follow-up surveys were conducted in the same manner as baseline surveys, save that the majority were
conducted via telephone. The surveys lasted 1-2 hours. Participants received $20 compensation for the baseline interview, $35 for the 12-month interview, and $40 for the 24-month interview.

3.2.4. Measures

The surveys consisted of a large number of standardised items and measures. The following section lists the specific items used in this study. All items, except where noted, were identical across the three survey waves. All measures were recoded into binary format (0 = no, 1 = yes), for the purposes of bivariate and multivariate analyses, if not originally coded as such. The specific details of how this was undertaken, where applicable, is also outlined in the following sections.

3.2.4.1. Demographics

Young people were asked basic demographic and identity questions, which included date of birth, gender (1 = female, 2 = male) and sexual identity (1 = heterosexual, 2 = bisexual, 3 = gay or homosexual, 4 = lesbian, 5 = insure or undecided). Age in years was calculated from the date of birth using the following formula: age = (Interview data – Date of birth)/365.25. Sexual identity (0 = heterosexual, 1 = bisexual, gay, lesbian or unsure) and age (0 = 12 to 17 years, 1 = 18 years and older) were recoded into binary format for statistical analyses.

3.2.4.2. Living arrangements

Living arrangements in the baseline survey were measured by asking young people to state all places they had ever lived for more than two days (excluding holidays), beginning with the first place they had lived and ending with their current living place. Periods as a ward of the State, in secure welfare and in Juvenile Justice or prison were included. Young people’s responses were categorised according to 21 housing types,
which included: birth (biological) family home; foster family home; step-family home; 
grandparent's home; relative's home; friend's house; family group home; boarding 
school; early adolescent unit; medium-term accommodation; refuge, shelter or single-
room occupancy; hotel, motel; secure welfare unit; juvenile detention centre, jail; Job 
Corps facility; psychiatric hospital; caravan park; adoptive family home; own 
apartment; street, squat, abandoned building; and other. Young people were also asked 
to report the length of time they had stayed in each place (1 = less than a month, 2 = 1-3 
months, 3 = 4-6 months, 4 = 7-12 months, 5 = 1-5 years, 6 = 5-10 years, 7 = 10+ years).

This series of questions was then used to form binary variables measuring whether a 
young person had resided in a particular living arrangement in the three months before 
the baseline survey. Three months was chosen as the interval for which to base these 
questions as it was comparable to all other questions contained in the baseline survey. A 
young person was determined to have lived at a particular place if they reported living 
there at least once in the three months before the baseline survey. The three-month 
period was calculated by summing half of the nominal interval indicated in the second 
half of the question beginning with their current living arrangement and working 
backwards in chronological order until a total of three months (12 weeks) had been 
reached. While this is a relatively crude procedure it provides the closest approximate 
measure, on average, to the actual (unrecorded) time period with the available data.

Living arrangements in the 12- and 24-month surveys were measured by presenting 
young people with a list of 21 accommodation types (as listed above) and asking 
“during the last 6 months, have you lived in any of the following places” (0 = no, 1 = 
yes).

Living arrangement variables for all survey points were reduced to eight categories for 
the statistical analyses. These included parent’s home (biological family, stepfamily, 
adoptive family and foster family); relative’s home (grandparents and relative’s home); 
friend’s house; medium-term accommodation; refuge shelter, single-room occupancy; 
juvenile detention centre or jail; own apartment; and street, squat or abandoned 
building. The categories of housing including family group home, boarding school,
early adolescent unit, hotel or motel, secure welfare unit, psychiatric hospital, caravan park were not used in analyses due to very low prevalence rates.

3.2.4.3. Education and Income

Young people were asked several questions about participation in education and sources of income. Young people were asked if they were currently attending school; trade school; Technical and Further Education (TAFE); Job Placement, Employment and Training (JPET) program; or university (0 = no, 1 = yes) and, if they had a job in the last three months (0 = no, 1= yes). A job was defined as employment in which they were paid with a cheque, direct deposit into a bank account, or cash in hand. Young people were also asked “are you currently receiving the Youth Allowance” (0 = no, 1 = yes).

Income derived from alternative sources was also assessed. In the baseline surveys, young people were asked to indicate if they had supported themselves in the last three months by: “having or trading sex for money”, “borrowing money from friends”, “selling drugs”, “gambling or gambling-related activities”, “stealing”, “pornography (photos, video, film)”, “having or trading sex for a place to stay”, “begging or scamming”, and “hocking or selling goods”. Young people were asked to respond no (0) or yes (1) to each. In the 12- and 24-month surveys, young people were asked the same items, except in reference to the last six months.

To reduce the total number of alternative sources of income for the bivariate and multivariate analyses a factor analysis was conducted. The analysis of a large sample of young people who experienced homelessness (unpublished data) indicated two factors: sex-related sources of income (Cronbach’s $\alpha = .646$) and other sources of income ($\alpha = .636$). These factors were recoded into binary variables. Sex-related alternative sources of income consisted of having or trading sex for a place to stay, having or trading sex for money, and pornography (0 = no to all questions, 1 = yes to one or more questions). Other sources of income consisted of borrowing money from friends, selling drugs,
gambling or gambling-related activities, stealing, begging or scamming and hocking or selling goods (0 = no to all questions, 1 = yes to one or more questions).

3.2.4.4. Drug Use

A modified version of the National Household Survey on Drug Abuse (National Institute on Drug Abuse, 1991) was used to measure drug use practices. Young people were questioned about nine types of drugs: marijuana, inhalants, ecstasy, amphetamines or speed, cocaine or crack, hallucinogens, heroin, non-medical use of sedatives or tranquillisers, and non-medical use of analgesics or painkillers. They were asked to indicate how many days in the last three months (0-90 days) they had used the drug and, if relevant to the particular class of drug, whether they had injected it (0 = no, 1 = yes).

The drug use variables were recoded into binary format for the statistical analyses (0 = used the drug on zero days in the last three months, 1 = used the drug on one or more days in the last three months). To reduce the total number of variables examined, sedatives and analgesics were collapsed to form “non-prescription drugs” and ecstasy, cocaine and amphetamines were collapsed to form “stimulant drugs”. These groups were based on the class of the drug, similarity of affect on the central nervous system and patterns of cross-usage (Mallett et al., 2003). Items regarding injecting drug use were combined to form a single variable for the bivariate and multivariate analyses (0 = injected no drugs, 1 = injected one or more type of drugs).

3.2.1.5. Sexual Practices

Sexual practices were measured in two ways. First, young people were asked if they had engaged in vaginal or anal sex in the last three months (0 = no, 1 = yes). Secondly, they were asked four questions about involuntary sex. They were asked “in the past three months have you had sex when you did not want to because”: “you were too drunk at the time”, “you were too high at the time”, “you felt unable to say no”, and “you said no but the person did not listen” (0 = no, 1 = yes to each). Items regarding involuntary sex
were combined to form a single variable for the bivariate and multivariate analyses (0 = no to all questions, 1 = yes to one or more questions).

A measure of safe sex (i.e. condom use) was not able to be used in these analyses because of the manner in which it was measured. Items about condom use were only asked to those who had engaged in sex during the past three months on each survey wave and its use would have substantially reduced the sample size at each survey wave. Moreover, the nominal response categories of the condom use items did not provide a valid response for those who had not engaged in sexual practices.

3.2.4.6. Blood-borne Virus Risk

A modified version of the Blood-Borne Virus Transmission Risk Assessment Questionnaire (BBV-TRAQ, Fry et al., 1998b) was used. Young people were asked to indicate the number of times in the last three months they had: “injected with another person’s used needle or syringe”; “injected after using other people’s equipment (e.g. water, spoon, tourniquet, swab or spoon)”; “been tattooed by someone who was not a professional tattooist”; “been pierced (e.g. ear or body) by someone who was not a professional piercer”; “used another person’s used razor (e.g. disposal razors, razor-blades)”; “used another person’s toothbrush”; and “used another person’s personal hygiene equipment (e.g. nail file, nail scissors, nail clippers, tweezers, comb, brush)”?

Each of these variables were recoded into binary variables for the statistical analyses (0 = engaged in the practice zero times in the last three months, 1 = engaged in the practice one or more times in the last three months). Due to the very low prevalence of each covariate and the similar nature of the practices, sharing needles and sharing injecting equipment were combined to form a single variable (0 = no to both questions, 1 = yes to either question). Due the low prevalence of tattooing and the similarity of the practices, pierced by a non-professional and tattooed by a non-professional were also combined to form a single variable (0 = no to both questions, 1 = yes to either question).
3.2.4.7. Health

Young people were asked several questions about their physical, mental and sexual health. Young people were asked “in general, how would you describe your health” (1 = excellent, 2 = good, 3 = fair, 4 = poor)? This rating was recoded into a binary variable for the statistical analyses (0 = poor and fair health, 1 = excellent or good health).

The Brief Symptom Inventory ([BSI] Derogatis, 1993) was used to assess mental health. The BSI was shortened to include only five of the nine sub-scales: anxiety, depression, somatisation, obsessive-compulsive, and hostility. These scales were measured via 34 items. Young people were asked to rate how much each statement (e.g. trouble remembering things, feeling lonely, thoughts of death or dying) had bothered them during the last week, including today, on a five-point Likert-type scale, from “not at all” (0) to “extremely” (4). Standardised clinical cut-off scores were used to generate binary variables for each of the five sub-scales. Young people were coded as not having possible mental health problems (0), if their sub scale score was below the standardised cut-off score, or as having possible mental health problems (1) (i.e. depression), if their sub scale score was above the cut-off score.

Self-harm was measured by asking young people, “in the last three months how many times have you deliberately hurt yourself or done something that you knew might hurt you”. Self-harm was recoded into a binary variable for the bivariate and multivariate analyses (0 = no, 1 = yes). Suicide was measured by asking “in the last three months, have you attempted suicide” (0 = no, 1 = yes). In the 12- and 24-month surveys, young people were asked the same items, except in reference to the last six months.

Young people were asked three questions about testing for infections. They were asked “have you been tested for HIV in the last 3-months” (0 = no, 1 = yes), “have you been tested for hepatitis C in the last 3-months” (0 = no, 1 = yes) and “have you been tested for sexually transmitted diseases in the last 3-months” (0 = no, 1 = yes). Young people were also questioned about pregnancy. Female participants were asked: “during the past three months, did you find out that you were pregnant or had a baby” (1 = no, 2 =
pregnant, 3 = had a baby). Male participants were asked the same questions but in reference to their partners. Pregnancy was recoded into binary format for the statistical analyses (0 = did not have a baby or became pregnant, 1 = had a baby or became pregnant).

3.2.4.8. Service Utilisation

Young people were asked several questions about their use of community services. Identical questions were asked in reference to ten issues: housing, depression or anxiety, drug and alcohol use, school problems, work or employment, family problems, general health problems, pregnancy, legal issues, and income support. Young people were asked “in the last three months, did you feel you needed help for [issue]” (0 = no, 1 = yes) and if yes, “did you go for help” (0 = no, 1 = yes). In the 12- and 24-month surveys, young people were asked the same items, except in reference to the last six months.

Young people were also questioned about their use of five specific types of services. They were asked to indicate the number of time in last three months they had: “visited a needle exchange program”, “actually entered or started an alcohol or drug treatment program”, “participated in a detox program”, “been an inpatient or stayed in a hospital overnight or longer” and “received care in a casualty department or accident and emergency”. These variable were recoded into binary format for the statistical analyses (0 = used the service zero times in the past three months, 1 = used the service on one or more occasions in the past three months).

Young people were asked two questions about case management. They were asked “do you have a case manager?” (0 = no, 1 = yes) and if yes, “do you have a case plan?” A case manager was defined to young people as a youth or social worker who coordinates the services they receive.
3.3. Results

3.3.1. Response Rate

A total of 437 surveys were completed by young people who had experienced homelessness over the three survey waves: 165 surveys were completed at baseline, 141 at the 12-month follow-up (85.5% of baseline sample), and 131 at the 24-month follow-up (79.4% of the baseline sample). The majority of young people (75.8%) completed all three surveys, while 18 (10.9%) completed only the baseline survey.

3.3.2. Data Storage and Warehousing

The electronic file generated from each survey was collated and stored in an electronic data warehouse (QDS, 1998). Data screening was undertaken at this stage to ensure that values were correctly recorded. Three SPSS datasets, one for each survey wave, were extracted from the electronic warehouse. The datasets were then combined to form a single dataset with responses from each survey wave for the same individual stored as separate records. Variable construction and generation of descriptive statistics were undertaken using SPSS Version 12 (2004) and all bivariate and multivariate statistical analyses were conducted using Stata Version 8 (2004). The SPSS dataset was converted into a Stata dataset using Stat Transfer Version 6 (2001).

3.3.3. Data Analysis

Two separate sets of statistical analyses were conducted on the longitudinal survey data. The first analysis focused on determining the prevalence of hepatitis C testing and the second analysis focused on determining the incidence of new cases of hepatitis C testing. Both analyses examined the association with a range of behavioural and contextual factors. The outcome and covariates in all analyses were coded in binary format. The statistical models utilised for each of these analyses were based on Carlin,
Wolfe, Coffey and Patton’s (1999; Patton et al., 1998a, 1998b) approach to analysing binary outcomes in longitudinal studies.

The analyses of the prevalence and incidence of testing was performed using concurrent data, that is, recent and first time testing was related to covariates that occurred within the same period of time. This decision was made on consideration of the interval between an event (e.g. engaging in injecting drug use) and hepatitis C testing observed in the limited published research and the current availability of statistical models. Previous research indicates that many people seek testing for hepatitis C and/or HIV, particularly after experiencing a risk, within a short period of time (Hughes, 2002; Loxley et al., 2000) however, for some people, events more remote to testing were important precipitants for testing, although it is unclear exactly how distant in time to testing these events occurred (Loxley et al., 2000). The interviews with young people presented in the Chapter 4 also confirms the variability in the timing of testing in relation to the reason for testing, although most were within a short period of time. Given the importance of immediate events to testing for many people, and the ambiguity of defining a meaningful interval for past events (i.e. choosing which of the past survey waves to use to predict testing), which may in fact be covered within the time interval covered by items in the surveys, concurrent covariates were chosen to predict testing.

3.3.4. Prevalence of Hepatitis C Testing

3.3.4.1. Statistical Methods

The analysis of the prevalence of hepatitis C testing involved three steps: 1) determining the prevalence rate of hepatitis C testing across each of the three survey waves; 2) examining the bivariate association between each covariate and hepatitis C testing prevalence; and 3) building a multivariate model of the factors associated with hepatitis C testing prevalence.
3.3.4.1.1. Prevalence

The prevalence of hepatitis C testing for each survey wave was defined as the proportion of young people who reported being tested for hepatitis C in the past three months. Separate prevalence rates were calculated for each survey wave.

3.3.4.1.2. Bivariate Associations

Examination of the bivariate association between each covariate and hepatitis C testing was undertaken in two steps. First, a descriptive (non-statistical) account of the association between each covariate and hepatitis C testing was generated by crosstabulating each covariate and hepatitis C testing. Second, each pair was submitted to a statistical analysis using a logistic regression model. The model was fitted in Stata using a generalised estimating equation (GEE) approach with robust standard errors (see Appendix B). GEE was used rather than a standard logistic regression model, as it allowed the examination of survey panel-data and provided a means of controlling the clustering which occurred due to participants contributing multiple cases to the dataset (Carlin et al., 1999).

The GEE model also contained a parameter for survey wave (denoted “time” in Appendix B) to control for the strong association between survey wave and hepatitis C testing. As will be discussed in detail below, the baseline or background prevalence of hepatitis C testing significantly increased over the survey waves. The results that are reported below indicate the effect of the covariate in question after controlling for the effect of survey wave. It should be noted that the survey wave was significantly associated with the outcome measure in all bivariate and multivariate analyses (p<.005).

3.3.4.1.3. Multivariate Associations

The multivariate analysis was performed using the same generalised estimating equation as described for the bivariate analyses. A step-wise selection procedure was used to
construct the multivariate model, beginning with the covariate with the strongest association. The step-wise selection procedure was chosen, as it provided a strategy to reduce the large number of covariates to a set that most accurately predicted the hepatitis C testing (Tabachnick & Fidell, 1996). The entry and exit criteria were set at p-value<.2. This cut-off value was chosen because it is standard practice in step-wise procedures and is a conservative approach to developing a multivariate model which ensures that all covariates that may be important in the context of other covariates (i.e. in a multivariate model) are included (Tabachnick & Fidell, 1996).

The interaction between each covariate and survey wave, as a predictor of hepatitis C testing, was also explored. The results of these analyses indicated whether the effect of each covariate on hepatitis C testing was consistent across the survey waves or whether it varied across the survey waves. Three covariates were found to have a significant interaction with survey wave: depression, employment, and having lived in a refuge. These covariates were, however, not retained in the final multivariate model and consequently the interaction parameters were not introduced.

3.3.4.2. Hepatitis C Testing Prevalence

The prevalence of hepatitis C testing among the young people surveyed was relatively high and consistently rose over the course of the study. At the baseline survey, a little under one-third (31.1%) of young people reported ever having a hepatitis C test. Of those who had ever been tested, 45.1% (13.9% of the sample) reported being tested in the past three months. The prevalence of hepatitis C testing significantly rose across the two follow-up survey waves, \( X^2 (2) = 13.33, p = .001 \). At the 12-month follow-up survey 22.3% of young people reported being tested for hepatitis C in the past three months, while at the 24-month follow-up 31.5% reported being tested.

Seventy-two young people (43.6%) reported being tested in the past last three months on at least one survey. Although no data were collected on the frequency of testing at each survey wave, the majority (72.2%) of young people who reported being tested for hepatitis C at some stage during the course of the study did so at only one survey.
Furthermore, 17 young people (23.6% of those who had been tested) reported being tested for hepatitis C in two surveys and only three young people reported being tested in all three surveys.

### 3.3.4.3. Bivariate Associations with the Prevalence of Hepatitis C Testing

#### 3.3.4.3.1. Socio-demographics and Living Arrangements

A number of socio-demographic variables were examined for an association with hepatitis C testing prevalence (see Table 3). Young people’s gender and sexual identity appeared to be related to the likelihood of having been recently tested for hepatitis C. Young men appeared to be less likely than young women to have been tested for hepatitis C, while the odds of young people who identified as gay, lesbian, bisexual, or were undecided about their sexual identity being tested for hepatitis C were slightly over twice that of those who identified as heterosexual. Only sexual identity, however, was statistically significant. The age of young people was not related to hepatitis C testing prevalence.

Young people who were currently in education were generally less likely than those who were not currently in education to have been tested for hepatitis C. There was however, no evidence of a statistically significant relationship.

The income source of young people appeared to have some relationship to hepatitis C testing prevalence. The odds of young people who received a government allowance being tested were over 1.5 times higher than those who did not receive a government allowance, while the odds of young people who supported themselves through other sources of income, such as selling drugs, begging, borrowing money from friends, gambling, stealing or hocking goods, being tested for hepatitis C were over two times higher. Young people who supported themselves through sex-related sources of income, such as sex-work or pornography, were also appeared more likely to have been tested for hepatitis C, however there was no evidence of a statistical relationship. Young
people who had been employed in the period before each survey were no more likely to have been tested for hepatitis C than those who had not been employed.

Table 3. Percentage of young people who were tested for hepatitis C in the last three months by socio-demographic variables and survey wave

<table>
<thead>
<tr>
<th>Socio-demographics</th>
<th>Baseline</th>
<th>12-months</th>
<th>24-months</th>
<th>Logistic regression</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Age</td>
<td>12.7</td>
<td>16.4</td>
<td>24.1</td>
<td>21.2</td>
</tr>
<tr>
<td>Gender</td>
<td>17.1</td>
<td>10.4</td>
<td>24.7</td>
<td>19.4</td>
</tr>
<tr>
<td>Sexuality</td>
<td>13.0</td>
<td>18.5</td>
<td>19.3</td>
<td>36.0</td>
</tr>
<tr>
<td>Currently in education</td>
<td>19.5</td>
<td>9.1</td>
<td>20.9</td>
<td>24.5</td>
</tr>
<tr>
<td>Employed</td>
<td>8.5</td>
<td>19.3</td>
<td>29.2</td>
<td>18.7</td>
</tr>
<tr>
<td>Receive the Youth Allowance</td>
<td>12.9</td>
<td>13.8</td>
<td>11.7</td>
<td>30.4</td>
</tr>
<tr>
<td>Alternative sources of income:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sex-related</td>
<td>13.8</td>
<td>25.0</td>
<td>22.8</td>
<td>0.0</td>
</tr>
<tr>
<td>Other sources **</td>
<td>10.5</td>
<td>18.6</td>
<td>18.3</td>
<td>25.3</td>
</tr>
</tbody>
</table>

*p-value <.2 *p<.05 **p<.01 ***p<.001; 1 = reference category is 12-17 years; 2 = reference category is female; 3 = reference category is heterosexual

A number of living arrangements were related to hepatitis C testing (see Table 4). Young people were significantly more likely to have been tested for hepatitis C if, in the same period of time, they had lived at a friend’s house, spent time in juvenile justice or gaol, or had lived on the streets or in a squat. Young people who had lived in a refuge or crisis-accommodation also appeared more likely to have been tested for hepatitis C, however this relationship was statistically non-significant. Living in medium-term or
transitional accommodation, at a relative’s house, in one’s own place, or a parent’s house was unrelated to hepatitis C testing prevalence.

Table 4. Percentage of young people who were tested for hepatitis C in the last three months by living arrangements and survey wave

<table>
<thead>
<tr>
<th>Living arrangements</th>
<th>Baseline 12-months 24-months</th>
<th>Logistic regression</th>
<th>Lower CI</th>
<th>Upper CI</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Refuge*</td>
<td>18.0</td>
<td>9.9</td>
<td>16.8</td>
<td>46.2</td>
</tr>
<tr>
<td>Medium-term accommodation</td>
<td>13.7</td>
<td>15.0</td>
<td>22.6</td>
<td>21.2</td>
</tr>
<tr>
<td>Relatives</td>
<td>14.6</td>
<td>11.1</td>
<td>22.0</td>
<td>25.0</td>
</tr>
<tr>
<td>Friends*</td>
<td>10.7</td>
<td>16.7</td>
<td>20.5</td>
<td>25.0</td>
</tr>
<tr>
<td>Own place</td>
<td>13.9</td>
<td>0.0</td>
<td>23.2</td>
<td>19.4</td>
</tr>
<tr>
<td>Parents</td>
<td>18.8</td>
<td>11.7</td>
<td>21.5</td>
<td>23.3</td>
</tr>
<tr>
<td>Juvenile justice or gaol*</td>
<td>13.4</td>
<td>50.0</td>
<td>20.6</td>
<td>100.0</td>
</tr>
<tr>
<td>Streets or squat*</td>
<td>13.3</td>
<td>25.0</td>
<td>21.8</td>
<td>33.3</td>
</tr>
</tbody>
</table>

#p-value <.2 *p<.05 **p<.01 ***p<.001

3.3.4.3.2. Drug Use

The results of the bivariate analyses indicated that young people who had used illicit drugs in the past three months were generally more likely to have been tested for hepatitis C in the same three-month period (see Table 5). More specifically, young people who had used marijuana, stimulant drugs, such as ecstasy, cocaine or amphetamines, sedatives or analgesics for nonmedical reasons, and heroin were significantly more likely than those who had not used these drugs to have been tested for hepatitis C. There was no evidence for a statistical relationship between the use of inhalants and hepatitis C testing or the use of hallucinogens and hepatitis C testing, although there was a tendency for young people who had used either class of drug to be more likely to have been tested for hepatitis C.
The strongest association between a measure of drug use and hepatitis C testing was with injecting drug use. The odds of young people who had injected one or more of the injectable classes of drugs in the past three months being tested for hepatitis C was over four times higher those who had not injected.

Table 5. Percentage of young people who were tested for hepatitis C in the last three months by drug use and survey wave

<table>
<thead>
<tr>
<th>Drug</th>
<th>Baseline</th>
<th>12-months</th>
<th>24-months</th>
<th>Logistic regression</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Marijuana**</td>
<td>7.7</td>
<td>18.2</td>
<td>13.4</td>
<td>30.6</td>
</tr>
<tr>
<td>Inhalants</td>
<td>14.9</td>
<td>8.3</td>
<td>21.9</td>
<td>30.0</td>
</tr>
<tr>
<td>Hallucinogens #</td>
<td>13.5</td>
<td>16.7</td>
<td>22.1</td>
<td>28.6</td>
</tr>
<tr>
<td>Heroin**</td>
<td>13.3</td>
<td>23.1</td>
<td>21.6</td>
<td>50.0</td>
</tr>
<tr>
<td>Sedative or analgesics***</td>
<td>11.7</td>
<td>22.2</td>
<td>18.8</td>
<td>40.9</td>
</tr>
<tr>
<td>Stimulant drugs**</td>
<td>11.0</td>
<td>19.6</td>
<td>18.4</td>
<td>28.9</td>
</tr>
<tr>
<td>Injecting drug use ***</td>
<td>12.6</td>
<td>28.6</td>
<td>20.9</td>
<td>40.0</td>
</tr>
</tbody>
</table>

*p-value <.2 *p<.05 **p<.01 ***p<.001

3.3.4.3.3. Sexual Practices

Two measures of sexual contact were examined for an association with hepatitis C testing (see Table 6). Young people who reported having vaginal or anal sex in the past three months tended to be more likely to have been tested for hepatitis C than those who had not had sex. Young people who reported involuntarily sex were marginally more likely to have been tested for hepatitis C. There was, however, no evidence for a statistical relationship between these variables and recent testing.
### Table 6. Percentage of young people who were tested for hepatitis C in the last three months by sexual contact and survey wave

<table>
<thead>
<tr>
<th>Sexual contact</th>
<th>Baseline</th>
<th>12-months</th>
<th>24-months</th>
<th>Logistic regression</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Vaginal or anal sex*</td>
<td>6.7</td>
<td>18.1</td>
<td>20.0</td>
<td>23.1</td>
</tr>
<tr>
<td>Involuntary sex</td>
<td>13.7</td>
<td>14.3</td>
<td>21.3</td>
<td>29.4</td>
</tr>
</tbody>
</table>

#p-value <.2 *p<.05 **p<.01 ***p<.001

### 3.3.4.3.4. Blood-borne Virus Risk

A surprising finding of the bivariate analyses was that standardised measures of blood-borne virus risk were unrelated to hepatitis C testing (see Table 7). Young people who reported sharing needles, syringes or injecting equipment; being pierced or tattooed by a non-professional; or using another's razor tended to be more likely than those who had not engaged in these practices to report also being tested for hepatitis C. There was, however, no evidence for a statistical relationship between these variables and recent testing. Young people who reported using another's hygiene products or another's toothbrush were no more likely to have been tested for hepatitis C than those who did not.
Table 7. Percentage of young people who were tested for hepatitis C in the last three months by blood-borne virus risk and survey wave

<table>
<thead>
<tr>
<th>Blood-borne virus risk</th>
<th>Baseline No</th>
<th>Baseline Yes</th>
<th>12-months No</th>
<th>12-months Yes</th>
<th>24-months No</th>
<th>24-months Yes</th>
<th>Logistic regression AOR</th>
<th>Lower CI</th>
<th>Upper CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Shared needles, syringes or equipment#</td>
<td>14.0</td>
<td>14.3</td>
<td>22.0</td>
<td>33.3</td>
<td>30.5</td>
<td>100.0</td>
<td>2.16</td>
<td>0.71</td>
<td>6.56</td>
</tr>
<tr>
<td>Pierced or tattooed by non-professional</td>
<td>13.8</td>
<td>15.8</td>
<td>21.1</td>
<td>40.0</td>
<td>31.2</td>
<td>37.5</td>
<td>1.56</td>
<td>0.71</td>
<td>3.43</td>
</tr>
<tr>
<td>Used another's razor#</td>
<td>12.8</td>
<td>17.0</td>
<td>20.2</td>
<td>31.0</td>
<td>29.8</td>
<td>38.5</td>
<td>1.51</td>
<td>0.89</td>
<td>2.57</td>
</tr>
<tr>
<td>Used another's toothbrush</td>
<td>12.7</td>
<td>20.0</td>
<td>23.1</td>
<td>19.1</td>
<td>30.9</td>
<td>35.0</td>
<td>1.20</td>
<td>0.64</td>
<td>2.25</td>
</tr>
<tr>
<td>Used another's hygiene products</td>
<td>13.6</td>
<td>14.3</td>
<td>21.3</td>
<td>23.7</td>
<td>33.3</td>
<td>29.1</td>
<td>0.93</td>
<td>0.58</td>
<td>1.50</td>
</tr>
</tbody>
</table>

#p-value <.2 *p<.05 **p<.01 ***p<.001

3.3.4.3.5. Health

A number of health measures were examined for a relationship with hepatitis C testing prevalence (see Table 8). Although the self-reported rating of current health appeared to have little relationship with hepatitis C testing prevalence, the odds of young people who had given birth or become pregnant (in the case of young men, their partners) being tested for hepatitis C were over 3 ½ times higher than young people who had not given birth or become pregnant.

There was no apparent relationship between self-harm or attempted suicide and hepatitis C testing, however young people who recorded high scores on the five BSI sub-scales were generally more likely to have been tested for hepatitis C. The results of the bivariate statistical analyses indicated that only the depression sub-scale was a significant predictor of recent hepatitis C testing. Accordingly, the odds of young people who reported high depression scores being tested or hepatitis C were over two times higher than those who reported low depression scores.
Young people who had been tested for HIV or STIs in the past three months were considerably more likely to have also been tested for hepatitis C. The odds of young people who had been tested for HIV being tested for hepatitis C were over 200 times higher than those who had not been tested for HIV, while the odds of those who had been tested for STIs were over 150 times higher. The odds ratios for these covariates are exceptionally high and suggest a structural relationship with hepatitis C testing rather than a genuine predictive relationship. Due to the extremely high odd ratios and possible structural relationship, HIV and STI testing were excluded from the multivariate analysis. Despite this, the importance of HIV and STI testing in understanding the patterns of hepatitis C testing is acknowledged.

Table 8. Percentage of young people who were tested for hepatitis C in the last three months by health measures and survey wave

<table>
<thead>
<tr>
<th>Health</th>
<th>Baseline No</th>
<th>Baseline Yes</th>
<th>12-months No</th>
<th>12-months Yes</th>
<th>24-months No</th>
<th>24-months Yes</th>
<th>Logistic regression AOR</th>
<th>Lower CI</th>
<th>Upper CI</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>13.5</td>
<td>24.4</td>
<td>24.4</td>
<td>21.4</td>
<td>0.68</td>
<td>0.41</td>
<td>1.11</td>
</tr>
<tr>
<td>Health rating</td>
<td></td>
<td></td>
<td></td>
<td>15.2</td>
<td>13.5</td>
<td>24.4</td>
<td>21.4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pregnancy</td>
<td></td>
<td></td>
<td></td>
<td>11.8</td>
<td>38.5</td>
<td>21.4</td>
<td>37.5</td>
<td>3.69</td>
<td>1.67</td>
</tr>
<tr>
<td>Attempted suicide</td>
<td>13.9</td>
<td>14.3</td>
<td>21.9</td>
<td>27.3</td>
<td>31.0</td>
<td>50.0</td>
<td>1.19</td>
<td>0.50</td>
<td>2.84</td>
</tr>
<tr>
<td>Self harmed</td>
<td>14.4</td>
<td>13.4</td>
<td>21.2</td>
<td>26.9</td>
<td>30.5</td>
<td>36.0</td>
<td>1.09</td>
<td>0.63</td>
<td>1.90</td>
</tr>
<tr>
<td>Somatisation</td>
<td>12.7</td>
<td>21.7</td>
<td>23.1</td>
<td>16.7</td>
<td>28.8</td>
<td>47.4</td>
<td>1.39</td>
<td>0.73</td>
<td>2.66</td>
</tr>
<tr>
<td>Obsessive-compulsive</td>
<td>14.5</td>
<td>12.1</td>
<td>21.6</td>
<td>26.1</td>
<td>27.2</td>
<td>48.2</td>
<td>1.41</td>
<td>0.80</td>
<td>2.49</td>
</tr>
<tr>
<td>Depression</td>
<td>15.0</td>
<td>8.3</td>
<td>21.4</td>
<td>37.5</td>
<td>26.1</td>
<td>73.3</td>
<td>2.22</td>
<td>1.13</td>
<td>4.39</td>
</tr>
<tr>
<td>Anxiety</td>
<td>15.3</td>
<td>4.8</td>
<td>20.6</td>
<td>50.0</td>
<td>28.6</td>
<td>50.0</td>
<td>1.48</td>
<td>0.73</td>
<td>3.00</td>
</tr>
<tr>
<td>Hostility</td>
<td>14.2</td>
<td>12.5</td>
<td>21.7</td>
<td>30.0</td>
<td>28.5</td>
<td>57.1</td>
<td>1.72</td>
<td>0.83</td>
<td>3.59</td>
</tr>
<tr>
<td>Tested for HIV</td>
<td>3.6</td>
<td>72.0</td>
<td>5.4</td>
<td>92.6</td>
<td>1.2</td>
<td>90.9</td>
<td>201.1</td>
<td>83.16</td>
<td>486.2</td>
</tr>
<tr>
<td>Tested for STI</td>
<td>4.1</td>
<td>85.0</td>
<td>3.8</td>
<td>81.8</td>
<td>4.5</td>
<td>90.2</td>
<td>153.5</td>
<td>68.79</td>
<td>347.7</td>
</tr>
</tbody>
</table>

*p-value <.2 *p<.05 **p<.01 ***p<.001; 1 = reference category is ‘poor or fair’ health; 2 = become pregnant or had baby
3.3.4.3.6. Service Utilisation

Seeking help was related to the prevalence of hepatitis C testing for a number of different issues (see Table 9). Young people who reported seeking help for homelessness or housing, depression or anxiety, general health, pregnancy, legal issues or income support were significantly more likely than those who had not sought help for such needs to have been tested for hepatitis C. Seeking help for issues, such as drug or alcohol use, school problems, work or employment, or family problems, were not related to hepatitis C testing. In the case of seeking help for drug or alcohol use, there was a non-statistical trend for those who had sought help to be more likely to have also been recently tested for hepatitis C.

**Table 9. Percentage of young people who were tested for hepatitis C in the last three months by issues for which they sought help and survey wave**

<table>
<thead>
<tr>
<th>Sought help for:</th>
<th>Baseline No</th>
<th>12-months Yes</th>
<th>24-months Yes</th>
<th>Logistic regression AOR Lower CI</th>
<th>Upper CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Homelessness or housing **</td>
<td>7.1</td>
<td>15.3</td>
<td>40.6</td>
<td>29.4</td>
<td>42.9</td>
</tr>
<tr>
<td>Depression or anxiety *</td>
<td>13.6</td>
<td>15.6</td>
<td>36.0</td>
<td>26.3</td>
<td>45.7</td>
</tr>
<tr>
<td>Drug and/or alcohol problems</td>
<td>13.5</td>
<td>25.0</td>
<td>40.0</td>
<td>31.5</td>
<td>33.3</td>
</tr>
<tr>
<td>School problems</td>
<td>16.3</td>
<td>5.6</td>
<td>22.1</td>
<td>23.5</td>
<td>27.3</td>
</tr>
<tr>
<td>Work or employment</td>
<td>11.2</td>
<td>19.0</td>
<td>22.7</td>
<td>21.4</td>
<td>39.3</td>
</tr>
<tr>
<td>Family problems</td>
<td>15.5</td>
<td>4.4</td>
<td>22.1</td>
<td>25.0</td>
<td>30.9</td>
</tr>
<tr>
<td>General health ***</td>
<td>11.7</td>
<td>18.5</td>
<td>40.0</td>
<td>23.8</td>
<td>44.0</td>
</tr>
<tr>
<td>Pregnancy **</td>
<td>13.6</td>
<td>20.0</td>
<td>19.5</td>
<td>54.6</td>
<td>29.1</td>
</tr>
<tr>
<td>Legal issues **</td>
<td>11.9</td>
<td>23.3</td>
<td>36.8</td>
<td>27.0</td>
<td>57.9</td>
</tr>
<tr>
<td>Income support *</td>
<td>12.1</td>
<td>15.2</td>
<td>20.2</td>
<td>28.6</td>
<td>26.4</td>
</tr>
</tbody>
</table>

#p-value<.2 *p<.05 **p<.01 ***p<.001

Accessing a number of specific types of services also appeared to be related to hepatitis C testing prevalence (see Table 10). Young people who had stayed in hospital as an in-
patient (i.e. one or more nights in hospital) in the past three months were significantly more likely to have been tested for hepatitis C, as were those who had accessed an accident and emergency department. Somewhat surprisingly, young people who had accessed a drug or alcohol treatment program or a detoxification service were no more likely to have been tested for hepatitis C than those who had not accessed such services. Accessing a NSP was highly related to hepatitis C testing. The odds of young people who accessed a NSP in the past three months being tested for hepatitis C were almost seven times higher than those who had not accessed a NSP to have in the same three month period.

Young people who reported having a case manager, that is a youth or social worker who coordinated the services they received, were no more likely to have been tested for hepatitis C than those who did not have a case manager. If the young person reported having a case plan, they were generally more likely to have been recently tested for hepatitis C. This trend, however, only approached significance.

Table 10. Percentage of young people who were tested for hepatitis C in the last three months by services used and survey wave

<table>
<thead>
<tr>
<th>Services used</th>
<th>Baseline</th>
<th>12-months</th>
<th>24-months</th>
<th>Logistic regression AOR</th>
<th>Lower CI</th>
<th>Upper CI</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stayed in hospital</td>
<td>12.3</td>
<td>22.2</td>
<td>17.8</td>
<td>47.6</td>
<td>2.27</td>
<td>1.27</td>
</tr>
<tr>
<td>Used accident and emergency**</td>
<td>13.5</td>
<td>16.7</td>
<td>18.1</td>
<td>43.5</td>
<td>2.09</td>
<td>1.20</td>
</tr>
<tr>
<td>Entered drug/alcohol treatment</td>
<td>12.9</td>
<td>33.3</td>
<td>22.2</td>
<td>33.3</td>
<td>2.08</td>
<td>0.66</td>
</tr>
<tr>
<td>Entered detox</td>
<td>13.3</td>
<td>33.3</td>
<td>22.6</td>
<td>0.0</td>
<td>2.02</td>
<td>0.46</td>
</tr>
<tr>
<td>Accessed a NSP***</td>
<td>11.7</td>
<td>50.0</td>
<td>20.6</td>
<td>57.1</td>
<td>6.96</td>
<td>2.80</td>
</tr>
<tr>
<td>Case manager</td>
<td>16.7</td>
<td>11.5</td>
<td>19.6</td>
<td>27.7</td>
<td>0.93</td>
<td>0.56</td>
</tr>
<tr>
<td>Case plan#</td>
<td>12.5</td>
<td>19.1</td>
<td>20.2</td>
<td>36.8</td>
<td>1.72</td>
<td>0.93</td>
</tr>
</tbody>
</table>

*p-value <.2 **p<.05 ***p<.01
A total of 32 variables were considered for inclusion in the multivariate model, as they had a p-value less than .2 in the bivariate analyses. Using a step-wise selection procedure, the final multivariate model included nine covariates (see Table 11). The order the variables were entered, from first to last, was: 1) accessed a NSP, 2) sought help for general health issues, 3) used sedative or analgesics, 4) stayed in hospital, 5) sought help of legal issues, 6) become pregnant or had a baby, 7) sought help for homelessness, 8) sexuality, and 9) sought help for income support. At step 9, living at a friend’s house was entered, however with the addition of sought help for income support at step 10, it exceeded the retention criteria and was subsequently removed from the model.

Of the nine covariates retained in the multivariate model, six remained significantly related to recent hepatitis C testing (see Table 11). In addition to the effect of survey wave, young people were significantly more likely to have been tested for hepatitis C if they had accessed a NSP (AOR=4.90), sought help for general health problems (AOR=2.33), sought help for legal issues (AOR=2.02), became pregnant or had a baby (AOR=2.85), stayed in hospital as an inpatient (AOR=2.27) or used sedatives or analgesics (AOR=2.04).

The confidence interval for each of the independent predictors was typically large. This indicates that, although these covariates are important to predicting hepatitis C testing, the true population parameter or effect size is likely to differ from those observed in this study. The width of the confidence interval for sedative or analgesics use, sought help for general health issues, sought help for legal issues, and stayed in hospital was between 2.5 and 3.2. The width of the confidence intervals for pregnancy (5.5) and accessing a NSP (12.4) were considerable larger. These large confidence intervals were primarily due to the small sample size and/or the low prevalence of some covariates over the course of the study. The latter reason particularly applies to pregnancy and accessing a NSP.
### Table 11. Multivariate associations with the prevalence of hepatitis C testing in the last three months

<table>
<thead>
<tr>
<th></th>
<th>AOR</th>
<th>Std. Err.</th>
<th>z</th>
<th>p-value</th>
<th>Lower CI</th>
<th>Upper CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Accessed a NSP</td>
<td>4.90</td>
<td>2.64</td>
<td>2.95</td>
<td>0.003</td>
<td>1.71</td>
<td>14.08</td>
</tr>
<tr>
<td>Pregnancy(^1)</td>
<td>2.85</td>
<td>1.25</td>
<td>2.39</td>
<td>0.017</td>
<td>1.21</td>
<td>6.74</td>
</tr>
<tr>
<td>Sexuality(^2)</td>
<td>1.77</td>
<td>0.56</td>
<td>1.80</td>
<td>0.072</td>
<td>0.95</td>
<td>3.30</td>
</tr>
<tr>
<td>Sought help for general health</td>
<td>2.33</td>
<td>0.62</td>
<td>3.17</td>
<td>0.002</td>
<td>1.38</td>
<td>3.94</td>
</tr>
<tr>
<td>Sought help for homelessness</td>
<td>1.71</td>
<td>0.59</td>
<td>1.57</td>
<td>0.117</td>
<td>0.87</td>
<td>3.36</td>
</tr>
<tr>
<td>Sought help for income support</td>
<td>1.51</td>
<td>0.46</td>
<td>1.36</td>
<td>0.175</td>
<td>0.83</td>
<td>2.74</td>
</tr>
<tr>
<td>Sought help for legal issues</td>
<td>2.02</td>
<td>0.68</td>
<td>2.09</td>
<td>0.037</td>
<td>1.04</td>
<td>3.92</td>
</tr>
<tr>
<td>Stayed in hospital</td>
<td>2.27</td>
<td>0.74</td>
<td>2.50</td>
<td>0.012</td>
<td>1.20</td>
<td>4.32</td>
</tr>
<tr>
<td>Used sedative or analgesics</td>
<td>2.04</td>
<td>0.68</td>
<td>2.12</td>
<td>0.034</td>
<td>1.05</td>
<td>3.93</td>
</tr>
<tr>
<td>Time at 12 months</td>
<td>3.73</td>
<td>1.50</td>
<td>3.27</td>
<td>0.001</td>
<td>1.69</td>
<td>8.20</td>
</tr>
<tr>
<td>Time at 24 months</td>
<td>7.03</td>
<td>3.00</td>
<td>4.57</td>
<td>0.000</td>
<td>3.05</td>
<td>16.21</td>
</tr>
</tbody>
</table>

*p<.05 **p<.01 ***p<.001; 1 = become pregnant or had baby; 2 = reference category is heterosexual

#### 3.3.5. Incidence of Hepatitis C Testing

##### 3.3.5.1. Statistical Methods

The analysis of the incidence of hepatitis C testing focused on the transition to being tested for hepatitis C for the first time during the three waves of data collection. A transition was defined as a change from reporting no hepatitis C testing in the three months before the baseline survey to reporting hepatitis C testing in the three months before one of the two follow-up surveys. The analysis focused on only the first transition even though it is possible to make repeated transitions. The analysis of the incidence of hepatitis C testing involved four steps: 1) generating a time-to-event dataset; 2) estimating the incidence of first hepatitis C test within the time frame of the study; 3) examining the bivariate association between each covariate and the incidence of first hepatitis C test; and 4) building a multivariate model of the factors associated with the incidence of first hepatitis C test.
3.3.5.1.1. Survival-time Dataset

The survival-time dataset was generated using the *stset* command in Stata (see Appendix B). The failure event was defined as responding “yes” to having been tested for hepatitis C testing in the past three months. The date of each survey interview was used to calculate the quantity of time each participant contributed to the analysis at each survey wave. The analysis was performed on the age scale, rather than the time to follow-up scale, to avoid the need to adjust for age in the analysis.

3.3.5.1.2. Incidence Rate

The average incidence rate of first hepatitis C test, within the timeframe of the study, was calculated by dividing the number of incident cases by total-person years (Patton et al., 1998a, 1998b).

3.3.5.1.3. Bivariate Associations

Three statistics were generated to examine the bivariate association between each covariate and the incidence of first hepatitis C test: 1) incidence rate for each level of the covariates, 2) crude rate ratio (RR) for each covariate; and 3) unadjusted rate ratio using the discrete-time survival model for each covariate.

The incidence rate for each level of the covariates was calculated using the procedure outlined above for the average incidence rate (Patton et al., 1998a, 1998b). The crude RR is the ratio of the incidence rate of first hepatitis C test for those at a particular level of a covariate to the rate in the baseline or reference category of the covariate. Person-years for crude estimates were calculated using the midpoint between surveys for those who transitioned to being tested for hepatitis C and the full amount of time between surveys for those who made no transition to being tested for hepatitis C. The crude rate ratios were generated using a log discrete-time survival model and were fitted in Stata.
using a standard generalised linear model (see Appendix B). Robust standard errors were used to adjust for clustering due to multiple cases from each participant.

The association between each covariate and the transition to first hepatitis C test was then tested using a discrete-time survival model that accounts for the interval censored nature of these data explicitly, rather than via approximating the event time (Carlin et al., 1999). These models were fitted in Stata via a standard generalised linear model. Robust standard errors were used to adjust for clustering due to multiple cases from each participant and obtained via a modified sandwich method. A parameter for survey wave (denoted “time” in Appendix B) was included, as occurred in the prevalence analyses, to control for variations in the baseline incidence rate of hepatitis C testing across survey waves. Unlike the prevalence analyses, survey wave did not appear to have a significant effect on the incidence of hepatitis C testing, however it was still retained in all models to ensure an accurate as possible estimation of bivariate associations.

An issue that emerged during the analysis of the incidence of first hepatitis C test was that data had also been collected at the baseline survey on whether young people had been tested for hepatitis C at any stage during their lifetime, in addition to the past three months. As will be discussed below, some young people, who were included in the incidence analysis, according to the criteria that they had not been tested for hepatitis C in the three months before the baseline survey, had in fact been tested for hepatitis C at a time before the three months prior baseline. These data clearly pose an issue for an analysis focusing on the transition from not having been tested for hepatitis C to having been tested for hepatitis C. To overcome this issue these data three strategies were explored.

The first strategy was to exclude those who had “ever” been tested for hepatitis C at the baseline survey from the incidence analysis; leaving a sample containing only those who had never previously been tested for hepatitis C. This was the preferred strategy, as it provided a clean and uncomplicated definition of new cases of hepatitis C testing. This option did, however, reduce the number of transitions by approximately 40% and
produced a sample size that was too small to conduct a meaningful statistical analysis. The second strategy was to undertake a stratified analysis (by historical testing) of the incidence of first hepatitis C testing. This option also produced a sample size that was too small to conduct a meaningful statistical analysis.

The third strategy, which was ultimately adopted, was a compromise between retaining sufficient sample size and conducting a traditional discrete-time survival analysis and involved including a parameter for historical hepatitis C testing at baseline (denoted “prevtest” in Appendix B) to control for the effect it may have on transitions that occurred within the timeframe of the study. The results of the statistical analyses that follow are then interpreted as the association between each covariate and the transition to first hepatitis C testing during the three waves of data collection, after controlling for the effects of historical testing and survey wave. Previous testing was significantly associated with the outcome measure in all bivariate and multivariate analyses.

### 3.3.5.1.4. Multivariate Associations

The multivariate analysis was performed using the same complementary log-log discrete-time survival model as was used to test bivariate associations. A step-wise selection procedure was used to construct the multivariate model, beginning with the covariate with the strongest association. The entry and exit criteria was set at p<.2. The stepwise selection procedure was chosen, as was the case in the prevalence analysis, to reduce the large number of covariates to a set that most accurately predicted hepatitis C testing (Tabachnick & Fidell, 1996).

### 3.3.5.2. Rate of Hepatitis C Testing Incidence

A total of 49 young people made a transition from not being tested for hepatitis C in the three month before the baseline survey to being tested for hepatitis C for the first time. These participants contributed 220 person years to the analysis, which resulted in an average incidence rate of 0.222 (CI: 0.168 - 0.294) or 22% per person year. Twenty-six
of the 49 transitions occurred in the 12-month survey and 23 occurred in the 24-month survey.

3.3.5.3. Bivariate Associations with the Incidence of Hepatitis C Testing

3.3.5.3.1. Socio-demographics and Living Arrangements

The transition to being tested for hepatitis C for the first time was observationally, although not statistically, related to a number of socio-demographic variables (see Table 12). In a similar trend to the prevalence analysis, young women and young people who identified as gay, lesbian, bisexual or were undecided about their sexual identity appeared to be more likely to make a transition to being tested for hepatitis C for the first time. However, unlike the prevalence analyses, these trends were statistically non-significant. The age of young people was not related to being tested for hepatitis C for the first time.

Young people who were currently in education or who had been employed in the period before being surveyed were marginally less likely to make a transition to being tested for hepatitis C for the first time. Conversely, young people who received an income through a government allowance or through sex-related or other alternative sources of income were generally more likely to be tested for hepatitis C for the first time. There was, however, no evidence of a statistical relationship between the variables.
Table 12. Incidence of hepatitis C testing among young people by socio-demographic variables

<table>
<thead>
<tr>
<th>Socio-demographics</th>
<th>Incidence rate</th>
<th>Crude RR</th>
<th>Unadjusted RR</th>
<th>p-value</th>
<th>Lower CI</th>
<th>Upper CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age¹</td>
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<td>No</td>
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<td></td>
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<td></td>
</tr>
<tr>
<td>Yes</td>
<td>0.22</td>
<td>0.89</td>
<td>0.69</td>
<td>0.231</td>
<td>0.38</td>
<td>1.26</td>
</tr>
<tr>
<td>Gender²</td>
<td></td>
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<td></td>
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</tr>
<tr>
<td>No</td>
<td>0.28</td>
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<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Yes</td>
<td>0.16</td>
<td>0.55</td>
<td>0.61</td>
<td>0.108</td>
<td>0.33</td>
<td>1.11</td>
</tr>
<tr>
<td>Sexuality³</td>
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<td></td>
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<tr>
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<tr>
<td>Yes</td>
<td>0.38</td>
<td>2.17</td>
<td>1.68</td>
<td>0.133</td>
<td>0.85</td>
<td>3.13</td>
</tr>
<tr>
<td>Currently in education</td>
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<tr>
<td>No</td>
<td>0.24</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>0.18</td>
<td>0.70</td>
<td>0.73</td>
<td>0.343</td>
<td>0.38</td>
<td>1.40</td>
</tr>
<tr>
<td>Employed</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
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<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>0.20</td>
<td>0.72</td>
<td>0.78</td>
<td>0.416</td>
<td>0.42</td>
<td>1.43</td>
</tr>
<tr>
<td>Receive the Youth Allowance</td>
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<td></td>
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<tr>
<td>No</td>
<td>0.16</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>0.27</td>
<td>1.76</td>
<td>1.60</td>
<td>0.135</td>
<td>0.86</td>
<td>2.98</td>
</tr>
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<td>Alternative sources of income:</td>
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<td>Sex-related</td>
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<td>0.22</td>
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<td></td>
</tr>
<tr>
<td>Yes</td>
<td>0.32</td>
<td>1.70</td>
<td>1.94</td>
<td>0.190</td>
<td>0.72</td>
<td>5.22</td>
</tr>
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<td>Other sources</td>
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<td></td>
<td></td>
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</tr>
<tr>
<td>No</td>
<td>0.17</td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>0.27</td>
<td>1.70</td>
<td>1.54</td>
<td>0.161</td>
<td>0.84</td>
<td>2.84</td>
</tr>
</tbody>
</table>

RR = Rate Ratio; 1 = reference category is 12-17 years; 2 = reference category is female; 3 = reference category is heterosexual

A number of living arrangements were examined for an association with the transition to being tested for hepatitis C for the first time (see Table 13). Young people who had lived in a refuge or crisis-accommodation were significantly more likely to transition to being tested for hepatitis C testing for the first time. Young people who had resided in juvenile justice or on the streets or in a squat also appeared to be more likely to make the transition to being tested for hepatitis C however, there was no evidence of a statistical relationship. Living at a parent’s house, in medium-term or transitional
accommodation, at a relative’s house, in one’s own place, or at a friend’s house were unrelated to the transition to first time hepatitis C testing.

Table 13. Incidence of hepatitis C testing among young people by living arrangements

<table>
<thead>
<tr>
<th>Living arrangement</th>
<th>Incidence rate</th>
<th>Crude RR</th>
<th>Unadjusted RR</th>
<th>p-value</th>
<th>Lower CI</th>
<th>Upper CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Refuge</td>
<td></td>
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</tr>
<tr>
<td>No</td>
<td>0.19</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>0.38</td>
<td>2.27</td>
<td>2.68</td>
<td>0.003</td>
<td>1.39</td>
<td>5.15</td>
</tr>
<tr>
<td>Medium-term accommodation</td>
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<tr>
<td>No</td>
<td>0.23</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>0.21</td>
<td>0.91</td>
<td>1.27</td>
<td>0.523</td>
<td>0.61</td>
<td>2.62</td>
</tr>
<tr>
<td>Relatives</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>0.22</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>0.22</td>
<td>1.03</td>
<td>1.12</td>
<td>0.810</td>
<td>0.44</td>
<td>2.89</td>
</tr>
<tr>
<td>Friends</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>No</td>
<td>0.20</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>0.27</td>
<td>1.38</td>
<td>1.14</td>
<td>0.677</td>
<td>0.61</td>
<td>2.14</td>
</tr>
<tr>
<td>Own place</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>0.21</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>0.25</td>
<td>1.22</td>
<td>1.16</td>
<td>0.654</td>
<td>0.61</td>
<td>2.21</td>
</tr>
<tr>
<td>Parents</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>No</td>
<td>0.23</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>0.21</td>
<td>0.90</td>
<td>1.00</td>
<td>0.994</td>
<td>0.56</td>
<td>1.78</td>
</tr>
<tr>
<td>Juvenile justice or gaol</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>0.22</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>0.65</td>
<td>3.88</td>
<td>4.10</td>
<td>0.072</td>
<td>0.88</td>
<td>19.02</td>
</tr>
<tr>
<td>Streets or squat</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>0.21</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>0.53</td>
<td>3.09</td>
<td>2.26</td>
<td>0.093</td>
<td>0.87</td>
<td>5.87</td>
</tr>
</tbody>
</table>

RR = Rate Ratio

3.3.5.3.2. Drug Use

The rate of transition to being tested for hepatitis C for the first time was considerably higher for young people who had used a range of substances (see Table 14). The discrete-time survival analysis indicated that only the non-medical use of sedatives or analgesics, and stimulant drugs, such as ecstasy, cocaine or amphetamines, were
significant predictors of first time hepatitis C testing, after controlling for historical
testing before baseline and survey wave. The odds of young people who had used these
classes of substances to transition to being tested for hepatitis C for the first time were
approximately 2.5 and 2 times higher, respectively, than those who had not used these
classes of substances. The use of marijuana and heroin and engaging in injecting drug
use approached statistical significance.

Table 14. Incidence of hepatitis C testing among young people by drug use

<table>
<thead>
<tr>
<th>Drug</th>
<th>Incidence rate</th>
<th>Crude RR</th>
<th>Unadjusted RR</th>
<th>p-value</th>
<th>Lower CI</th>
<th>Upper CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Marijuana</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>0.17</td>
<td></td>
<td>1.76</td>
<td>0.060</td>
<td>0.98</td>
<td>3.18</td>
</tr>
<tr>
<td>Yes</td>
<td>0.28</td>
<td>1.78</td>
<td>1.76</td>
<td>0.060</td>
<td>0.98</td>
<td>3.18</td>
</tr>
<tr>
<td>Inhalants</td>
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<td></td>
</tr>
<tr>
<td>No</td>
<td>0.22</td>
<td></td>
<td>1.95</td>
<td>0.102</td>
<td>0.88</td>
<td>4.34</td>
</tr>
<tr>
<td>Yes</td>
<td>0.32</td>
<td>1.54</td>
<td>1.95</td>
<td>0.102</td>
<td>0.88</td>
<td>4.34</td>
</tr>
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<td>LSD</td>
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<td>No</td>
<td>0.22</td>
<td></td>
<td>2.22</td>
<td>0.226</td>
<td>0.61</td>
<td>8.04</td>
</tr>
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<td>Yes</td>
<td>0.45</td>
<td>2.51</td>
<td>2.22</td>
<td>0.226</td>
<td>0.61</td>
<td>8.04</td>
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<td>Heroin</td>
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<td>3.45</td>
<td>0.064</td>
<td>0.93</td>
<td>12.80</td>
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<td>2.89</td>
<td>3.45</td>
<td>0.064</td>
<td>0.93</td>
<td>12.80</td>
</tr>
<tr>
<td>Sedative or analgesics</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>0.19</td>
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<td>2.27</td>
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<td>1.11</td>
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<td>0.17</td>
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<td>2.00</td>
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<td>3.58</td>
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<td>Yes</td>
<td>0.32</td>
<td>2.10</td>
<td>2.00</td>
<td>0.020</td>
<td>1.12</td>
<td>3.58</td>
</tr>
<tr>
<td>Injecting drug use</td>
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<td>0.078</td>
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<td>0.55</td>
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<td>2.72</td>
<td>0.078</td>
<td>0.89</td>
<td>8.28</td>
</tr>
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</table>

RR = Rate Ratio

3.3.5.3.3. Sexual Practices

Two measures of sexual contact were examined for an association with first time testing
for hepatitis C (see Table 15). Young people who reported having vaginal or anal sex in
the past three months were generally more likely than those who had not engaged in sex to make the transition to being tested for hepatitis C. Similarly, young people who had involuntarily sex appeared more likely to make the transition. However, after controlling for historical testing before baseline and survey wave, there was no evidence of a statistical relationship between the variables.

Table 15. Incidence of hepatitis C testing among young people by sexual practice

<table>
<thead>
<tr>
<th>Sexual practice</th>
<th>Incidence rate</th>
<th>Crude RR</th>
<th>Complementary log-log survival model</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>Unadjusted RR</td>
</tr>
<tr>
<td>Vaginal or anal sex</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>0.14</td>
<td></td>
<td>1.76</td>
</tr>
<tr>
<td>Yes</td>
<td>0.26</td>
<td>1.98</td>
<td></td>
</tr>
<tr>
<td>Involuntary sex</td>
<td></td>
<td></td>
<td>1.87</td>
</tr>
<tr>
<td>No</td>
<td>0.20</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>0.35</td>
<td>1.89</td>
<td></td>
</tr>
</tbody>
</table>

RR = Rate Ratio

3.3.5.3.4. Blood-borne Virus Risk

The incidence rate of first time hepatitis C testing appeared to be associated with some blood-borne virus risk practices (see Table 16). In particular, young people who reported sharing needles, syringes or injecting equipment; being pierced or tattooed by non-professional; or using another's razor blade tended to be more likely to transition to being tested for hepatitis C for the first time. However, after controlling for historical testing before baseline and survey wave, these trends were statistically non-significant. The incidence rate of first time hepatitis C testing appeared to be marginally lower for young people who reported using another's toothbrush, however, the relationship was also statistically non-significant. Young people who reported using another’s hygiene products were no more likely to make the transition to being tested for hepatitis C.
Table 16. Incidence of hepatitis C testing among young people by blood-borne virus risk

<table>
<thead>
<tr>
<th>Blood-borne virus risk</th>
<th>Incidence rate</th>
<th>Crude RR</th>
<th>Unadjusted RR</th>
<th>p-value</th>
<th>Lower CI</th>
<th>Upper CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Shared needles, syringes or equipment</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>0.22</td>
<td>2.34</td>
<td>2.72</td>
<td>0.104</td>
<td>0.81</td>
<td>9.10</td>
</tr>
<tr>
<td>Yes</td>
<td>0.41</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pierced or tattooed by non-professional</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>0.21</td>
<td>1.90</td>
<td>1.86</td>
<td>0.241</td>
<td>0.66</td>
<td>5.22</td>
</tr>
<tr>
<td>Yes</td>
<td>0.37</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Used another's razor</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>0.20</td>
<td>1.57</td>
<td>1.73</td>
<td>0.096</td>
<td>0.91</td>
<td>3.30</td>
</tr>
<tr>
<td>Yes</td>
<td>0.30</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Used another's toothbrush</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>0.23</td>
<td>0.71</td>
<td>0.69</td>
<td>0.426</td>
<td>0.28</td>
<td>1.72</td>
</tr>
<tr>
<td>Yes</td>
<td>0.17</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Used another's hygiene products</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>0.22</td>
<td>1.08</td>
<td>0.86</td>
<td>0.641</td>
<td>0.45</td>
<td>1.63</td>
</tr>
<tr>
<td>Yes</td>
<td>0.23</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

RR = Rate Ratio

3.3.5.3.5. Health

The transition to being tested for hepatitis C was associated with a number of health measures (see Table 17). The incidence rate of first time hepatitis C testing appeared to be lower among young people who rated their health as excellent or good however, after controlling for historical testing before baseline and survey wave there was no evidence of a statistically significant relationship. Pregnancy (conceiving or giving birth), on the other hand, was highly associated with the incidence of first time hepatitis C testing. The odds of young people who had become pregnant or given birth (in the case of young men, their partners) to transition to first time hepatitis C testing were
approximately three and a quarter times higher than those who had not become pregnant or given birth.

In accordance with the prevalence analysis, self-harm and attempted suicide were not associated with the transition to first time testing for hepatitis C. There was however, some association with the BSI sub-scales. Young people who reported high depression or anxiety scores were significantly more likely to transition to first time testing for hepatitis C. There was little or no association between somatisation, obsessive-compulsive, or hostility scores and the transition to being tested for hepatitis C for the first time.

Testing for HIV and testing for STIs were highly associated with the transition to hepatitis C testing. After controlling for historical testing before baseline and survey wave, the odds of young people who were tested for HIV in the past three months being tested for hepatitis C for the first time were over 90 times higher than those who had not been tested for HIV, while the odds of young people who had been tested for STIs were almost 48 times higher. The odds ratio for these covariates are exceptionally high and, as with the prevalence analysis, suggests a structural relationship with hepatitis C testing rather than a genuine predictive relationship. As a result, these variables were excluded from the multivariate analysis.
Table 17. Incidence of hepatitis C testing among young people by health measures

<table>
<thead>
<tr>
<th>Health Measure</th>
<th>Incidence rate</th>
<th>Complementary log-log survival model</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Crude RR</td>
</tr>
<tr>
<td>Health rating¹</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>0.31</td>
<td>0.56</td>
</tr>
<tr>
<td>Yes</td>
<td>0.19</td>
<td>0.21</td>
</tr>
<tr>
<td>Pregnancy²</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>0.21</td>
<td>0.43</td>
</tr>
<tr>
<td>Yes</td>
<td>0.23</td>
<td>0.70</td>
</tr>
<tr>
<td>Attempted suicide</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>0.23</td>
<td>0.23</td>
</tr>
<tr>
<td>Yes</td>
<td>0.17</td>
<td>0.66</td>
</tr>
<tr>
<td>Self-harm</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>0.22</td>
<td>0.23</td>
</tr>
<tr>
<td>Yes</td>
<td>0.16</td>
<td>0.66</td>
</tr>
<tr>
<td>Somatisation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>0.23</td>
<td>0.23</td>
</tr>
<tr>
<td>Yes</td>
<td>0.25</td>
<td>1.17</td>
</tr>
<tr>
<td>Obsessive-compulsive</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>0.22</td>
<td>0.25</td>
</tr>
<tr>
<td>Yes</td>
<td>0.20</td>
<td>0.48</td>
</tr>
<tr>
<td>Depression</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>0.21</td>
<td>0.44</td>
</tr>
<tr>
<td>Yes</td>
<td>0.04</td>
<td>0.29</td>
</tr>
<tr>
<td>Anxiety</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>0.22</td>
<td>0.83</td>
</tr>
<tr>
<td>Yes</td>
<td>0.04</td>
<td>0.81</td>
</tr>
</tbody>
</table>

*RR = Rate Ratio; 1 = reference category is ‘poor or fair’ health; 2 = become pregnant or had baby

3.3.5.3.6. Service Utilisation

Seeking help for a number of different needs was associated with the transition to being tested for hepatitis C for the first time (see Table 18). After controlling for historical
testing before baseline and survey wave, young people who sought help for homelessness or housing, depression or anxiety, general health, pregnancy, or legal issues were significantly more likely than those who had not sought help for such needs to transition to being tested for hepatitis C. The incidence rate of first time hepatitis C testing was also higher among young people who had sought help for drug or alcohol problems, income support, and family problems, however, there was no evidence of a statistically significant relationship between these variables and testing. Seeking help for school problems or work or employment issues was not related to first time hepatitis C testing.
Table 18. Incidence of hepatitis C testing among young people by issues for which they sought help

<table>
<thead>
<tr>
<th>Sought help for:</th>
<th>Incidence rate</th>
<th>Crude RR</th>
<th>Unadjusted RR</th>
<th>p-value</th>
<th>Lower CI</th>
<th>Upper CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Homelessness or housing</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>0.18</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>0.39</td>
<td>2.41</td>
<td>2.08</td>
<td>0.037</td>
<td>1.05</td>
<td>4.14</td>
</tr>
<tr>
<td>Depression or anxiety</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>0.19</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>0.36</td>
<td>2.12</td>
<td>2.08</td>
<td>0.014</td>
<td>1.16</td>
<td>3.74</td>
</tr>
<tr>
<td>Drug and/or alcohol problems</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>0.22</td>
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<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>0.32</td>
<td>1.57</td>
<td>1.46</td>
<td>0.541</td>
<td>0.43</td>
<td>4.95</td>
</tr>
<tr>
<td>School problems</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>0.22</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>0.24</td>
<td>1.08</td>
<td>1.51</td>
<td>0.340</td>
<td>0.65</td>
<td>3.54</td>
</tr>
<tr>
<td>Work or employment</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>0.21</td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>0.26</td>
<td>1.31</td>
<td>1.10</td>
<td>0.777</td>
<td>0.57</td>
<td>2.10</td>
</tr>
<tr>
<td>Family problems</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>No</td>
<td>0.21</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>0.38</td>
<td>1.98</td>
<td>2.07</td>
<td>0.081</td>
<td>0.92</td>
<td>4.66</td>
</tr>
<tr>
<td>General health</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>0.14</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>0.40</td>
<td>3.35</td>
<td>3.21</td>
<td>0.000</td>
<td>1.82</td>
<td>5.66</td>
</tr>
<tr>
<td>Pregnancy</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>0.19</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>0.54</td>
<td>3.51</td>
<td>5.50</td>
<td>0.000</td>
<td>2.48</td>
<td>12.18</td>
</tr>
<tr>
<td>Legal issues</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>0.19</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>0.49</td>
<td>3.46</td>
<td>3.20</td>
<td>0.001</td>
<td>1.63</td>
<td>6.27</td>
</tr>
<tr>
<td>Income support</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>No</td>
<td>0.19</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>0.35</td>
<td>2.05</td>
<td>1.64</td>
<td>0.170</td>
<td>0.81</td>
<td>3.33</td>
</tr>
</tbody>
</table>

RR = Rate Ratio

Accessing a number of specific types of services also appeared to be associated with the transition to first time hepatitis C testing (see Table 19). Young people who stayed in hospital as an in-patient (i.e. one or more nights in hospital) were significantly more likely to transition to being tested for hepatitis C for the first time, as were those who
had accessed an accident and emergency department. Young people who accessed a NSP were also more likely to transition, however there was no evidence for a statistical relationship after controlling for historical testing before baseline and survey wave. Having a case manager or having a case plan were not significantly related to the transition to being tested for the first time for hepatitis C although, for the latter, incidence rates were somewhat higher.

No young people who had been tested for hepatitis C for the first time reported entering a drug or alcohol treatment program or detoxification service. As a consequence, incidence rates and associated statistics were not generated for these covariates.

**Table 19. Incidence of hepatitis C testing among young people by services used**

<table>
<thead>
<tr>
<th>Service used</th>
<th>Incidence rate</th>
<th>Crude RR</th>
<th>Unadjusted RR</th>
<th>p-value</th>
<th>Lower CI</th>
<th>Upper CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stayed in hospital</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>0.20</td>
<td>1.98</td>
<td>2.38</td>
<td>0.016</td>
<td>1.17</td>
<td>4.82</td>
</tr>
<tr>
<td>Yes</td>
<td>0.35</td>
<td>1.98</td>
<td>2.38</td>
<td>0.016</td>
<td>1.17</td>
<td>4.82</td>
</tr>
<tr>
<td>Accident and emergency</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>0.20</td>
<td>1.91</td>
<td>1.99</td>
<td>0.047</td>
<td>1.01</td>
<td>3.92</td>
</tr>
<tr>
<td>Yes</td>
<td>0.34</td>
<td>1.91</td>
<td>1.99</td>
<td>0.047</td>
<td>1.01</td>
<td>3.92</td>
</tr>
<tr>
<td>Accessed NSP</td>
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<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>0.21</td>
<td>3.98</td>
<td>2.31</td>
<td>0.191</td>
<td>0.66</td>
<td>8.81</td>
</tr>
<tr>
<td>Yes</td>
<td>0.58</td>
<td>3.98</td>
<td>2.31</td>
<td>0.191</td>
<td>0.66</td>
<td>8.81</td>
</tr>
<tr>
<td>Case manager</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>0.21</td>
<td>1.30</td>
<td>1.36</td>
<td>0.356</td>
<td>0.71</td>
<td>2.62</td>
</tr>
<tr>
<td>Yes</td>
<td>0.26</td>
<td>1.30</td>
<td>1.36</td>
<td>0.356</td>
<td>0.71</td>
<td>2.62</td>
</tr>
<tr>
<td>Case plan</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>0.21</td>
<td>1.73</td>
<td>1.75</td>
<td>0.156</td>
<td>0.81</td>
<td>3.77</td>
</tr>
<tr>
<td>Yes</td>
<td>0.33</td>
<td>1.73</td>
<td>1.75</td>
<td>0.156</td>
<td>0.81</td>
<td>3.77</td>
</tr>
</tbody>
</table>

**RR = Rate Ratio**

3.3.5.4. *Multivariate Associations with Incidence of Hepatitis C Testing*

A total of 33 variables were considered for inclusion in the multivariate model, as they had a p-value less than .2 in the bivariate analyses. Using a step-wise selection
procedure, the final multivariate model included eleven covariates (see Table 20). The order the variables were entered, from first to last, was: 1) sought help for pregnancy, 2) depression, 3) sought help of legal issues, 4) stayed in hospital, 5) sought help for general health issues, 6) engaged in sex-related alterative sources of incomes, 7) stayed in juvenile justice or gaol, 8) sought help for homelessness, 9) used stimulant substances, 10) become pregnant or having a baby, and 11) gender.

Of the eleven covariates retained in the multivariate model, seven were significantly related to hepatitis C testing. After controlling for historical testing before baseline and survey wave, young people who sought help for pregnancy (AOR=3.29), had high depression scores (AOR=3.93), sought help of legal issues (AOR=4.04), stayed in hospital as an inpatient (AOR=4.74), sought help for general health issues (AOR=2.13), engaged in sex-related alterative sources of incomes (AOR=3.76), or used stimulant substances (AOR=1.90) were significantly more likely to have made the transition to being tested for hepatitis C for the first time. The confidence interval for each of the independent predictors was typically large, as in the prevalence analyses, and was primarily caused by the small sample size and small number of recorded transitions.
Table 20. Multivariate associations with the incidence of hepatitis C testing

<table>
<thead>
<tr>
<th></th>
<th>Adjusted OR</th>
<th>Robust Std. Err.</th>
<th>z</th>
<th>p-value</th>
<th>Lower CI</th>
<th>Upper CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Depression</td>
<td>3.93</td>
<td>1.82</td>
<td>2.96</td>
<td>0.003</td>
<td>1.59</td>
<td>9.74</td>
</tr>
<tr>
<td>Gender</td>
<td>0.54</td>
<td>0.20</td>
<td>-1.68</td>
<td>0.093</td>
<td>0.26</td>
<td>1.11</td>
</tr>
<tr>
<td>Pregnancy</td>
<td>2.91</td>
<td>1.67</td>
<td>1.87</td>
<td>0.062</td>
<td>0.95</td>
<td>8.93</td>
</tr>
<tr>
<td>Sex-related income sources</td>
<td>3.76</td>
<td>2.32</td>
<td>2.15</td>
<td>0.031</td>
<td>1.13</td>
<td>12.57</td>
</tr>
<tr>
<td>Sought help for general health</td>
<td>2.13</td>
<td>0.68</td>
<td>2.39</td>
<td>0.017</td>
<td>1.14</td>
<td>3.97</td>
</tr>
<tr>
<td>Sought help for homelessness</td>
<td>1.98</td>
<td>0.75</td>
<td>1.79</td>
<td>0.073</td>
<td>0.94</td>
<td>4.18</td>
</tr>
<tr>
<td>Sought help for legal issues</td>
<td>4.04</td>
<td>1.61</td>
<td>3.52</td>
<td>0.000</td>
<td>1.86</td>
<td>8.80</td>
</tr>
<tr>
<td>Sought help for pregnancy</td>
<td>3.29</td>
<td>1.47</td>
<td>2.67</td>
<td>0.008</td>
<td>1.37</td>
<td>7.90</td>
</tr>
<tr>
<td>Stayed in hospital</td>
<td>4.74</td>
<td>2.04</td>
<td>3.61</td>
<td>0.000</td>
<td>2.04</td>
<td>11.03</td>
</tr>
<tr>
<td>Stayed in JJ or gaol</td>
<td>2.43</td>
<td>1.40</td>
<td>1.54</td>
<td>0.124</td>
<td>0.78</td>
<td>7.53</td>
</tr>
<tr>
<td>Stimulant drugs</td>
<td>1.90</td>
<td>0.59</td>
<td>2.07</td>
<td>0.038</td>
<td>1.04</td>
<td>3.48</td>
</tr>
<tr>
<td>Previous testing</td>
<td>5.83</td>
<td>2.14</td>
<td>4.80</td>
<td>0.000</td>
<td>2.84</td>
<td>11.99</td>
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<tr>
<td>Time at 12 months</td>
<td>0.66</td>
<td>0.22</td>
<td>-1.24</td>
<td>0.215</td>
<td>0.35</td>
<td>1.27</td>
</tr>
</tbody>
</table>

*p<.05  **p<.01  ***p<.001; 1 = reference category is male; 2 = become pregnancy or had a baby JJ = Juvenile Justice

3.4. Summary of Results

3.4.1. Prevalence

The prevalence of recent hepatitis C testing (i.e. testing within the three months before each survey) was high among the young people surveyed and consistently rose over the course of the study (14%, 22% and 32% across the three survey waves). Furthermore, 31% had ever been tested at baseline and 44% had been tested at least once during the course of the study.

Recent hepatitis C testing was found to be associated with many self-reported behavioural and contextual variables. Young people who had used various types of drugs in the past three months, including marijuana, heroin, non-medical use of sedative or analgesics, and stimulant drugs were more likely to have been recently tested for
hepatitis C than those who had not used these drugs. Furthermore, young people who had engaged in injecting drug use were more likely to have been tested. Young people who described themselves as gay, bisexual, lesbian or were unsure about their sexual identity, were economically disadvantaged (i.e. received the Youth Allowance and derived income from ‘other’ alternative sources), and had recently lived with friends, in juvenile justice or on the streets were more likely to have been recently tested for hepatitis C, as were those who had become pregnant or had a baby (or their partner if male), been tested for HIV or STI, had high levels of depression, and had accessed services for variety of issues, including homelessness or housing, depression, general health, legal and income support. Young people who accessed a number of specific types of services were also more likely to have been tested for hepatitis C, including those who had accessed a needle and syringe exchange program, accessed an accident and emergency department or had stayed in hospital as an inpatient.

Many other variables appeared to be related to recent hepatitis C testing however, there was no evidence to suggest a statistically significant relationship. In particular and surprisingly, there was no evidence that standardised measures of blood-borne virus risk (i.e. sharing needles, syringes or equipment while injecting, being pierced or tattooed by a non-professional, and using another’s razor, toothbrush or other hygiene products) were related to recent hepatitis C testing.

Only six variables remained independently related to the prevalence of hepatitis C testing when included in a multivariate model. This model indicated that, after controlling for all other covariates and survey wave, young people were more likely to have been tested for hepatitis C if they had accessed a NSP, sought help for general health problems, sought help for legal issues, become pregnant or had a baby, stayed in hospital as an inpatient, or used sedatives or analgesics.

3.4.2. Incidence

The results of the incidence analysis revealed that 49 young people (29.7%) made a transition from not being tested to being tested for hepatitis C during the three waves of
data collection. The average incidence rate of first time testing was 0.222 or 22% per person years.

First time testing was found to be related to using sedatives or analgesics for non-medical reasons, using stimulant drugs, having recently lived in a refuge, becoming pregnant or having a baby (or their partner, if male), high levels of depression and anxiety, recent testing for HIV or STI, staying in hospital as an inpatient, accessing an accident and emergency department, and seeking help for a number of issues, including for homelessness or housing, depression, pregnancy and legal issues. As in the prevalence analysis, many other behavioural and contextual variables appeared to be related to first time testing however, there was little or no evidence of a statistically significant relationship. In particular, there was no evidence for a relationship between first time testing and standardised measures of blood-borne virus risk.

The multivariate analysis of first time hepatitis C testing incidence revealed some similarities to the prevalence analysis. After controlling for testing before baseline and survey wave, young people were significantly more likely to have been tested for hepatitis C for the first time if they had sought help for general health issues, sought help for legal issues and stayed in hospital as an inpatient. In addition to these characteristics, the incidence of new cases of testing was related to having sought help for pregnancy-related issues, high depression scores, engaging in sex-related alterative sources of incomes, and using stimulant drugs.

3.5. Discussion

The prevalence of hepatitis C testing observed among young people in this study is considerably higher than the prevalence observed in the broader Victorian population (Watson et al., 1999). Lifetime testing at the baseline survey was almost three times higher than the community estimate and four times higher by the completion of the study. The lifetime prevalence observed in this study is also much higher than the only other study that report testing rates among young people who experience homelessness (Lifson & Halcón, 2001). The lifetime prevalence rates observed here were, however,
similar to rates reported in studies examining people who inject drugs (Aitken, Kerger et al., 2002; Myers et al., 2005; Serfaty et al., 1997; Somaini et al., 2000). It should be noted that although the practice of injecting illicit drugs was more common among the young people in this study than among home-based young people (AIHW, 2002), it is still a relatively uncommon practice (7-8.5% at each survey wave) and, therefore, this sample should not be characterised as an injecting drug user sample. Although there are no direct comparisons for recent testing available in the literature, the prevalence of recent testing, particularly at the 12- and 24-month follow-up surveys, was much higher than the lifetime prevalence reported by Watson and colleagues (1999).

There have been no previous studies that have examined the incidence of new or first time hepatitis C testing among young people who experience homelessness or any other population. As such, the analysis undertaken as part of this study represents a novel direction for the understanding of who is tested for hepatitis C. Although direct comparisons are not available, the incidence rate observed in this study appear to be very high, even when compared to lifetime prevalence rates among the broader Victorian community (Watson et al., 1999).

The characteristics of those tested for hepatitis C is also quite different to previous research. One of the most consistent findings to emerge from previous research on hepatitis C testing, and indeed HIV testing, is that those who engage in scientifically identified risk practices, in particular injecting drug use, are more likely to be tested (Burchell et al., 2003; Grella et al., 1998; Rhodes et al., 2001; Serfaty et al., 1997; Van de Ven et al., 1999; Watson et al., 1999). This study, however, found little evidence that direct measures of blood-borne virus risk (as measured by modified items from the BBV-TRAQ) were related to hepatitis C testing in either the prevalence or incidence analysis. Recent injecting drug use did have a strong bivariate relationship with recent testing and a weak bivariate relationship with first time testing but, when the contribution of other factors were taken into account, it was not retained in the respective final models. These results are broadly consistent with Goldberg et al. (2005) who found no association between behaviour factors associated with the transmission of
hepatitis C and testing for hepatitis C among a cohort of adults with a psychotic or mood disorder in the United States.

The disparity in findings between this study and the majority of previous studies may reflect the range of variables examined. Previous studies have typically limited survey items to measures of blood-borne virus risk, a small number of variables relating to service utilisation (for other blood-borne viruses) and demographic characteristics. The limited range of variables included in these studies reflect, in part, that testing was not the primary focus and, therefore, may have had limited capacity to include an extensive array of other variables. It also reflects the dominance of the risk discourse within the hepatitis C and homelessness research. The exclusion of measures relating to social context may have led to other important explanatory variables being ignored, as was found to be the case in this study. This is not to argue that those who inject illicit drugs or engage in other practices deemed likely to transmit hepatitis C were not tested for hepatitis C or that it was not important for some of these young people. Rather, it is to argue that within the context of other factors examined in this study they were found to be less important. These findings, or lack thereof, may in fact reflect that many of those who had practiced injecting drug use had also not been tested. Of particular concern is that a little over one-quarter (28%) of young people who had injected drugs during the course of this study had also not been tested for hepatitis C within the same time period.

The characteristics that were found to be among the most important predictors of testing in this study related to contact with specific sections of the community and health service sector. In fact, four of the six variables retained in the final prevalence model and four of the seven variables retained in the final incidence model related to service use. Moreover, the characteristics of those who were tested for hepatitis C were similar, although not identical, between recent and first time testing. Obviously, to be tested for hepatitis C or another blood-borne virus requires contact with a health service, however these findings suggest that seeking help for a perceived need is more important to being tested than simply just engaging in a particular practice or displaying a particular characteristic, such as illness, gender, age, poverty or contact with the prison system. Further, it suggests that young people who experience homelessness are active in their
attempts to resolve the problems or issues they experience by accessing appropriate services, as has been observed in several studies (Barkin, Balkrishnan, Manuel, Anderson & Gelberg, 2003; de Rosa et al., 1999; Rew et al., 2002; Rossiter et al., 2003). It is unclear from these data whether young people specifically sought hepatitis C testing from these services. These data may indicate that young people were actively seeking testing and accessed services they believed offered testing. Alternatively, it may reflect that these young people were seeking assistance for an independent issue and the service provider assisting them suggested or recommended testing. There is some evidence from previous studies that testing, at least among injecting drug users, may be obtained opportunistically (Aitken, Kerger et al., 2002; Loxley et al., 2000), however it is not possible to further understand the relationship between contact with services and testing from the present data.

The specific nature of contact with the service sector that was found to be important in this study was not limited to the provision of services relating to other blood-borne viruses, such as testing and vaccination, as has been observed in previous studies (Rhodes et al., 2001, Watson et al., 1999). Each of the specific types of services that were found to be important are discussed in turn below.

Accessing a NSP was the strongest predictor of recent hepatitis C testing, although it had little association with first time testing. Needle and syringe programs are an important component of the broader public health response to hepatitis C in Australia and represent approximately 22% of total expenditure on hepatitis C prevention during 2004/05 in Australia (Gadiel & Powell, 2005). Exchanging used needles and syringes at an exchange program strongly suggests that these young people also engage in injecting drug use and, as such, can serve as an indirect measure of blood-borne virus risk. Unlike direct measures of blood-borne virus risk previously discussed however, accessing a NSP also implies that these young people were accessing and potentially injecting with new needles and syringes and may have adopted broader public health messages relating to injecting in a safer ways. Testing for hepatitis C may also be a part of this pattern of behaviour. There is some evidence suggesting that injecting drug users are more likely to access testing and other health services from sites that incorporate a
needle and syringe exchange program because they feel comfortable within the environment. Moreover, they do not feel comfortable accessing testing or help for other drug-related issues from other services, such as their regular general practitioner (Aitken, Kerger et al., 2002; Porter, Metzger & Scotti, 2002). Alternatively, this finding may reflect the structure of NSPs across Melbourne and the practices of many staff working at these services, which were revealed during conversations with many health workers in the sector over the course of this research. In particular, many NSPs in Melbourne are incorporated or co-located with health services and workers at these services actively promote and/or offer testing to their clients.

There was strong evidence indicating that accessing services for general health issues and staying in hospital as an inpatient were also related to hepatitis C testing. Although the specific issues for why young people accessed these types of services are unknown, these findings may reflect that young people viewed hepatitis C as a general health issue and actively sought testing. Two studies conducted in Australia report that the majority of hepatitis C tests occur within the confines of GP clinics (Myers et al. 2005; O’Brien et al., 2001), although testing during a hospital stay has not been noted before. Alternatively, these young people may have sought help for an independent health issue and were offered testing by the health practitioner as a consequence of a risk assessment, prejudice or standard practice. The association between seeking help for general health issues and staying in hospital with hepatitis C testing may also reflect the dominant stereotype held by many service providers that young people who experience homelessness are an at-risk group who engage in many practices, particularly injecting drug use, that place them at great risk of contracting hepatitis C and other infections (Mallett, Rosenthal & Myers, 2001; Myers et al., 2002). Such a belief may lead to a generalisation of the medical response to young people who are identified as homeless or transient. Presented with a young person who is at risk because they are homeless and who may not access the service again, many service providers may pursue testing because it is a good or only opportunity they have to test them.

Seeking help for legal issues was an important predictor of recent and first time hepatitis C testing. Contact with a prison system has been frequently linked to higher rates of
hepatitis C. These rates are believed to be caused, in part, by unsafe injecting, tattooing and piercing practices which occur within the prison environment (Crofts, 2001; MacDonald et al., 2001) but also because of the drug use and injecting histories of those entering the prison system (Feldman et al., 2004; Long et al., 2001). Moreover, there is an emphasis on testing for hepatitis C and other blood-borne viruses upon entry into the adult or juvenile detention systems, which has been confirmed as a location for testing in several studies (Loxley et al., 2000; Myers et al., 2005; O’Brien et al., 2001). Although this particular variable measures seeking help for legal problems, rather than actual contact with the prison system, it may indicate a similar trajectory or circumstance. There was some evidence of a bivariate relationship between having been in prison or detention and recent and first time testing however, there was no evidence of an association in final models. This was partly due to the very small number of young people (n=7) who actually reported staying in the prison system during the course of this study.

There was strong evidence indicating that pregnancy was related to hepatitis C testing. In the prevalence analysis, young people who became pregnant or had a baby (and in the case of young men, their partners) were more likely to be tested for hepatitis C. In the incidence analysis, on the other hand, it was the action of seeking help for pregnancy that was important, rather than the state of being pregnant or having a baby. Pregnancy (becoming pregnant or having a baby) was also retained in the final incidence model but only had a weak independent association. There was a tendency for young women who became pregnant or had a baby to be more likely, than young men whose partner became pregnant or had a baby, to have been tested, suggesting that many young women are tested for hepatitis C as part of antenatal care. This was examined statistically by introducing an interaction term between gender and pregnancy into each set of analyses, however there was no statistical evidence for this relationship. Given the low prevalence of these covariates (6-8% at each survey wave for pregnancy and 10% at each survey wave for seeking help for pregnancy-related issues) in this sample and that only one young man who had sought help for pregnancy issues or whose partner became pregnant (or had a baby) had also been tested to hepatitis C, there was unlikely to be sufficient power to adequately examine the interaction. There have
been a small number of studies examining the relationship between scientifically identified risk factors for hepatitis C and infection among pregnant women (e.g. Garner et al., 1997) however, the role of antenatal screening has not been discussed in the research literature. The national guidelines for hepatitis C testing (e.g. ANCAHRD, 2003) suggest that pregnant women should only be tested in the presence of a scientifically identified risk practice. The practice of offering testing to pregnant women was highlighted in conversations held with a number of health care workers during the course of this research. The description of their practices was very similar to the guidelines for testing and was typically only offered to those with an identified risk factor, primarily injecting drug use. These findings indicate that the approach may be more generalised.

There was some evidence in both sets of analyses indicating that the type of substance used is important in understanding hepatitis C testing. Young people who had used most types of substances in the past three months were more likely to be tested, though only the non-medical use of sedatives or analgesics was retained in the final prevalence model and only the use of stimulant drugs was retained in the final incidence model.

The relationship between the use of sedatives or analgesics and recent testing may reflect that some young people who used sedatives or analgesics also injected these drugs. Although only a small proportion of young people who used sedative or analgesics also injected them (8.3% at baseline, 4.5% at 12-months and 11.8% at 24-months), those who did were more likely to have been tested for hepatitis C than those who used these drugs in other ways. Due to the small number of young people who engaged in these practices, it was not possible to examine this hypothesis statistically. A second explanation for the importance of sedative or analgesic use, as a predictor of testing, is that the use of these drugs may reflect a constellation of issues that can lead to testing. There are many reasons why young people who experience homelessness use drugs (Mallett et al., 2003; Rayner, 2003), however there is some evidence to suggest that these classes of drugs are often used to alleviate physical and psychological symptoms (Klee & Reid, 1998b). Furthermore, those who self-medicate tend to use more types of drugs, inject drugs, and have poorer physical and mental health (Klee &
Reid, 1998b). This constellation of practices and issues would suggest a greater need to access health services and may alert a health care provider, among other issues, to a need for hepatitis C testing.

The association between the use of stimulants (i.e. ecstasy, amphetamines and cocaine) and testing may reflect the ways in which these drugs can be consumed. There is some evidence from previous research that the type of drug injected is associated with hepatitis C infection (Aitken, Kerger et al., 2002; Carruthers et al., 1997). The primary class of drug implicated is opiate-based substances, however some research suggests that injecting cocaine may also increase the likelihood of transmission because of the high frequency with which users typically inject themselves as a result of the short duration of the high (Greenfield et al., 1992; Hocking et al., 2001). A substantial minority (16.1% at baseline, 17.3% at 12-months, and 18.4% at 24-months) of young people who used stimulant drugs in this sample also injected them. Moreover, young people who injected these types of drugs were much more likely than those who used these drugs but did not inject them to have been tested for hepatitis C. Young people who use these stimulant drugs may still be seen as at risk for hepatitis C, even if they did not inject these drugs. There is some evidence that nasal inhalation of cocaine is related to hepatitis C transmission, as a result of bleeding from the nose due to the inhalation of these substances and sharing straws or other snorting equipment (Koblin, et al., 2003; MacDonald, et al., 2001). Although there is no evidence in the hepatitis C epidemiological research, this is presumably also true for the inhalation of amphetamines, which can also cause nasal bleeding.

Depression was strongly related to being tested for hepatitis C for the first time. There was also some evidence of a bivariate relationship between anxiety and testing but it was not retained in the final model. Diagnostic testing no matter the medical condition can be a very stressful event and can have a significant impact on mental health (Ickovics et al., 1998; Worthington & Myers, 2003). These results suggest that this is also likely to be the case for hepatitis C testing among young people who experience homelessness. Due to the manner in which these variables were measured, it is not possible to determine whether high levels of depression (and anxiety) occurred before
the test was undertaken, was a response to waiting for the test results or occurred after receiving the test results. However, it is likely that it was either after the test was undertaken but before the results were received or sometime after the results were received, as testing was measured in reference to the past three months and mental health was measured in reference to the past week.

The results of the longitudinal analyses also suggest that it is the first time young people are tested for hepatitis C that is particularly stressful, as these finding were stronger for first time testing than testing prevalence. There was some evidence for a relationship between depression and testing prevalence but it was not retained in the final multivariate model. The first time someone is tested for hepatitis C can be a particularly stressful event. A testee must not only confront the prospect that their own behaviours or circumstances have lead to the possibility that they have been exposed to the hepatitis C virus but also deliberate the possible outcomes of the serological test (i.e. that they may actually have hepatitis C). The first time someone is tested however, carries additional concerns about the procedures of the test itself, given that it would generally be unknown. There is also some evidence suggesting that those who are tested more often find the process of testing less stressful, as it becomes a more regular and familiar experience (Lupton et al., 1995).

There was some evidence that deriving income from sex-related sources of income was also important in predicting the incidence of first time hepatitis C testing. This has not been examined before in the hepatitis C testing literature but is similar to findings of de Rosa et al. (2001) who reported that survival sex, among other variables, was related to the prevalence of lifetime HIV testing among a sample of young people who experience homelessness in California, USA. Previous research with young people who engage in survival sex suggests that they are more likely to use condoms whilst engaging in sexual practices (Montgomery, Johnson, Kipke, Unger & Iverson, 1996 in de Rosa et al., 2001; Thomson, 1997). Testing may be a way of reducing concern about the practices in which they have engaged or provide them with certainty about their health in light of engaging in safer practices (de Rosa et al., 2001).
3.5.1. HIV and STI Testing

The results of both the prevalence and incidence analyses indicated a very strong relationship between hepatitis C testing, HIV testing and STI testing. In fact, 79% of those tested for hepatitis C had also been tested for HIV and one or more STIs. This finding is consistent with Loxley and colleagues’ (2000) observation that blood-borne virus testing (HIV, hepatitis B and hepatitis C) was typically undertaken as a battery of tests. They also reported that many of their participants thought of the battery of tests as a single test. Although Loxley and colleagues did not investigate STI testing, the results of this study indicate a very similar pattern of testing. It is possible that young people in this study also thought of these tests as a single test and responded in the affirmative to each infection when asked if they had been tested for it during the past three months. The results from the semi-structured interviews presented in Chapter 4 indicate however, that many young people were specific in their assertion that they had been tested for hepatitis C, even when it was as part of a larger number of tests. Some young people were unsure during the semi-structured interviews but on these occasions they were generally recounting testing events that had occurred a number of years prior. Alternatively, these results indicate that young people in this study were tested for all of these infections or diseases and reflect the practices of health care workers across Melbourne. Informal conversations held with many workers from services and agencies across Melbourne that provide blood-borne virus testing as all or part of their mandate support the latter interpretation. These workers indicated they routinely assess scientifically identified risk practices among their clients and offer appropriate testing.

3.5.2. Limitations

The results of the analyses presented from this study provide unique information to understand who is tested for hepatitis C among young people who experience homelessness in Melbourne. This contribution notwithstanding, there are a number of limitations of this study that warrant discussion. These limitations relate to the
representativeness of the sample, the size of the sample, and the use of concurrently measured covariates and outcome in the analyses.

First, the results of this study may not be representative of the broader population of young people who experience homelessness, as a purposive rather than random sample was employed. The use of a purposive sample was a pragmatic decision given the ‘hidden’ nature of the population. Young people who experience homelessness are often highly mobile in their living arrangements, are indistinguishable from home-based young people and do not necessarily identify themselves as homeless (Chamberlain & MacKenzie, 1998; Ringwalt, Greene, Robertson & McPheeters, 1998; Robertson, 1992). Some young people who experience homelessness are also thought to avoid contact or have no contact with the service sector (Chamberlain & MacKenzie, 1998). As such, it was not possible to employ a random sample and the findings presented here may, in part, reflect the bias inherent in a purposive sample.

The possible source of bias stems from the manner in which the young people were recruited into this study, namely, directly through community and health services in Melbourne. In an effort to minimise possible bias, young people were recruited from a diverse range of services. However, a substantial minority of the young people (approximately 15%) were recruited through one service. This service is the only state-wide housing and information and referral service for young people in Victoria and is the primary point of entry into the homeless service sector for young people. It is also co-located with many types of services including housing referral, health, legal, income support and computer access. A typical approach to young people accessing this service is to refer them to other services within the agency. Together these issues may limit the generalisability of these findings and may have lead to an overestimation of the importance of service use in predicting hepatitis C testing in this study.

There are a number of alternative approaches to sampling so-called hidden populations discussed within the health and social research fields that could have been used to recruit young people into this study, such as respondent-driven sampling (Heckathorn, 1997), targeted sampling (Watters & Biernacki, 1989) and snow-ball sampling
(Goodman, 1961). These methods were not used for a number of reasons. First, some of these methods (e.g. targeted sampling) have considerable start-up costs, as they require extensive examination of potential recruitment sites for their suitability and representativeness. This was well beyond the means of this research to implement. Secondly, this study was based upon an existing research project and consequently, the author did not have input into the initial sampling techniques. Thirdly, the approach ultimately adopted eliminated some of the bias associated with recruiting individuals through established social or peer networks and the ethical concerns about providing incentives to research participants to also recruit their peers into a study (e.g. respondent-driven sampling). Finally, as previously discussed, this research sought to recruit a diverse range of young people from a large number of service types in an effort to extend the current understanding of young people who experience homelessness beyond those recruited from street sites or crisis accommodation.

A second limitation of this study was the sample size employed. Although the sample was sufficient to perform the analyses presented, it was certainly not a large sample and produced the relatively large confidence intervals in the bivariate and multivariate analyses. The moderate sample size also meant that analyses were unlikely to have sufficient power to adequately examine the relationship between hepatitis C testing and covariates with a low baseline or background prevalence (e.g. entering drug treatment or a detoxification service, sharing needles and syringes, lived in juvenile detention) or to adequately investigate hypothesised interactions (e.g. between pregnancy and gender). The sample size achieved was a pragmatic decision in light of the difficulties and expense associated with longitudinal research and recruiting this population. A larger sample was well beyond the already extended budget of this study. The moderate sample size achieved was however, compensated by the longitudinal nature of the design. Surveying the same individual across multiple points in time reduces some on the error associated with cross-sectional designs and increases the power of analyses (Howell, 1997; Tabachnick & Fidell, 1996).

A final limitation of this study is that, while it provided a detailed understanding of the characteristics of those tested for hepatitis C at a population level, it did not and could
not provide insight into the circumstances or situations surrounding why an individual young person was tested for hepatitis C. In addition to being an important question in its own right, understanding these reasons would help interpret the results of this study beyond informed speculation. The next chapter seeks to elucidate this issue by examining the reasons why young people seek hepatitis C testing.
Chapter 4

Reasons for Hepatitis C Testing

The previous chapter examined patterns of hepatitis C testing among young people who experience homelessness in Melbourne and how they related to behavioural and contextual factors in order to determine the characteristics of those who are tested for hepatitis C. The findings of this study are important, as they provide evidence on whether those who are intended to receive testing are indeed those actually receive testing.

An allied and equally important issue relating to testing, which has received even less attention in the research literature, are the reasons for hepatitis C testing or why people are tested for hepatitis C. The current policies surrounding hepatitis C testing assume that testees have engaged in one or more scientifically identified risk practices and are active and informed participants in the process of testing. Furthermore, these policies assume testees voluntarily seek testing because they have engaged in a known risk practice or because a health practitioner has identified a risk in a client’s practices and suggested testing. The assumption in the latter scenario is that testing is still voluntary, as informed consent should be obtained. Whether this is actually the case in practice, remains unclear, as only two studies have examined this issue. These studies have exclusively recruited injecting drug users and used limited qualitative methods, namely open-ended survey questions delivered in an interview format. These studies indicate that injecting drug users often seek testing after engaging in a practice they perceived to be risky or of concern, because of opportunity, or out of concern for other people in their life (Aitken, Kerger et al., 2002; Loxley et al., 2000)

Understanding the motivations or circumstances behind testing provides valuable information for policies and services relating to testing. It provides insight into the concordance or discordance between the presumed motivations of those who undertake testing for hepatitis C (according to testing policy) and the motivations of those who are actually tested for hepatitis C. This knowledge would enable more tailored approaches
to testing to be developed, and hopefully more positive experiences and outcomes for testing recipients and broader public health concerns (Loxley et al., 2000).

The previous chapter utilised quantitative methods, namely longitudinal surveys, to examine patterns of hepatitis C testing. A series of self-reported closed questions were used to measure hepatitis C testing and a large number of covariates over three points in time. These measures were then examined for relationships through the use of several statistical procedures. These methods stem from a positivist or scientific ontological position and assume a reality that is objective and measurable. They do not and cannot consider the social, historical and cultural context within which the issues of interest occur (May, 2001; Lupton, 1999a). Further, they provide little insight into participants’ understanding or lived experience and, importantly, do not provide a means of answering the research questions that will be posed within this chapter in meaningful detail. Qualitative methods, on the other hand, allow such questions to be answered. Although a diverse collection of research strategies, these methods are used because it is process, meaning and experience, which is important rather than the amount, quantity, intensity or frequency (Denzin & Lincoln, 2000). Qualitative methods enable a rich body of material to be collected, which allows health issues, such as hepatitis C testing, to be examined from the participant’s experience and within the context they occur (Chamberlain et al., 1997; Hathaway, 1995).

The aim of this study is to examine the social, behavioural, psychological and environmental context in with hepatitis C testing occurs for young people who experience homelessness. In particular, this study seeks to answer the questions, why do young people who experience homelessness get tested for hepatitis C and what is the relationship between their reasons and their experience of homelessness, their gender and the way they manage their health more generally? These questions will be answered through the use of semi-structured qualitative interviews with a sub-sample of young people who participated in the longitudinal survey component two years after they were initially recruited.
4.1. Method

4.1.1. Participants

The participants of this study were 20 (12 female, 8 male) young people from the Project i longitudinal cohort. The average age of participants at the time of this study was 19.5 years and ranged from 17 to 22 years. Participants were recruited between April and September 2004.

4.1.2. Design

A semi-structured qualitative interview design was employed. Interviews were conducted after the final (24-month) longitudinal survey had been completed.

4.1.3. Procedure

4.1.3.1. Sampling Young People

A purposive sampling frame was adopted based upon the eligibility criteria for the longitudinal study described in Chapter 3 (3.2.1.), that is at the time of being recruited for the longitudinal study the participant was: 1) aged 12-20 years, 2) had spent the last two consecutive nights away from home (either without their parent’s or guardian’s permission, if under 17, or had been told to leave), and 3) had been living away from a parent or guardian for less than six months. Further to these criteria, participants must have reported having a hepatitis C test during at least one of the longitudinal surveys (i.e. baseline or 3, 6-, 12-, 18- or 24-month follow-up). Over half (92, 55.8%) of the young people were eligible to participate in Study 2.

Eligible young people were then assigned to one of four groups. Groups were formed by cross-tabulating self-reported hepatitis C status (positive or negative) and injecting drug use (yes or no). The majority of young people were categorised as hepatitis negative, no injecting drug use or hepatitis negative, injecting drug use (see Table 21). Hepatitis C
status and injecting drug use were chosen as dimensions to divide the sample because they allow a broad range of experiences to be heard as well as provide logical groups along which to initially compare the stories of those who have undertaken hepatitis C testing.

More specifically, hepatitis C status was chosen because receiving either a positive or negative test result may give rise to different experiences or memories of the testing process, as well as lead to different intentions or actual changes in health-related behaviour. Injecting drug use was chosen because engaging in the practice deemed the greatest danger of transmitting or contracting hepatitis C may give rise to very different motivations for seeking testing and expectations of the test result. Furthermore, injecting drug use was chosen, to the exclusion of other known or supposed risk practices (e.g. sharing razors and tattooing, or sharing razor blades) because it is the single largest practice that leads to transmission of hepatitis C, accounting for up to 80% of cases (Dore et al., 1999), and is the most probable practice that would lead to transmission among this population (Johnson et al., 1996; Lhuede & Moore, 1994).

Young people were defined as hepatitis C positive if they reported having had a positive hepatitis C test result on any of the longitudinal surveys. They were defined as having injected drugs if they reported injecting any of the six injectable substances (heroin, amphetamines, ecstasy, cocaine, sedatives or analgesics) on any of the longitudinal surveys.

<table>
<thead>
<tr>
<th>Injecting drug use</th>
<th>Self-reported hepatitis C status</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Negative</td>
</tr>
<tr>
<td>No</td>
<td>64</td>
</tr>
<tr>
<td>Yes</td>
<td>21</td>
</tr>
</tbody>
</table>

The sampling of specific participants from each group was undertaken according to a maximal variation framework. Within each group, an approximately equal number of
young men and young women were recruited, as were a diversity of ages, time since last hepatitis C test, and the apparent frequency of hepatitis C testing. Due to the low frequency of hepatitis C positive young people, all young people from the two groups of hepatitis C positive young people (injecting drug use yes/no) were invited to participate. The number of interviews conducted with young people from each group is shown in Table 22. Four of the seven young people who were hepatitis C positive were not interviewed because they were unable to be contacted.

<table>
<thead>
<tr>
<th>Table 22. Number of young people interviewed from each of the group</th>
</tr>
</thead>
<tbody>
<tr>
<td>Injecting drug use</td>
</tr>
<tr>
<td>No</td>
</tr>
<tr>
<td>8</td>
</tr>
<tr>
<td>Yes</td>
</tr>
</tbody>
</table>

4.1.3.2. Recruiting Young People

Selected participants were initially contacted via mail. The letter thanked them for being a part of Project i over the past two years and informed them of a new study that was underway. The letter invited them to participate in this new study and provided contact details (a free-call telephone number and email address) if they were interested. Young people were also told that whether they participated in the new study or not was entirely up to them and would not affect, in any way, their participation in Project i. If a young person had not made contact after 1-2 weeks (to allow time for the letter to be delivered and for the young person to consider their position) a follow-up phone call was made. Only two participants spontaneously responded to the initial letter, however many stated that they had intended to phone the free-call number but had been preoccupied with other matters or had not received the initial letter. If a young person was unable to be contacted after several attempts by telephone, mail and/or email then another participant from the same grouping was selected with similar characteristics to replace them (i.e. gender, age and testing history). Eight young people (5 male, 3 female) were unable to
be contacted; two (both male) refused to participate, due to being uninterested or having insufficient time; and three (2 male, 1 female) young people agreed to participate but withdrew before the interview could be undertaken, due to a death of a friend or having insufficient time to participate.

Once contact with the young person had been established, they were informed in detail of the nature and purpose of the research. If they agreed to participate in the study a mutually convenient time was arranged to conduct the interview. Interviews were generally scheduled only one to three days in advance, as appointments further in advance were generally not kept. Eleven of the twenty interviews occurred at the first scheduled interview time. The remaining interviews had to be rescheduled as the participant failed to show; on six occasions the interview was scheduled only one other time but on three occasions it was rescheduled a second time.

4.1.3.3. Conducting Interviews with Young People

Once the young person arrived at the scheduled time, they were greeted and thanked for attending. Time was taken to develop rapport; they were asked how their day had been thus far and about their experiences with Project i. They were then formally invited to participate in the study and informed consent was obtained (see Appendix C). As part of the informed consent process, young people were informed that interviewer was required to report current physical or sexual abuse (if under 17) and serious suicidal or homicidal feelings.

The interview was guided by a schedule of questions (see Table 23). The schedule of questions was developed from previous research, preliminary analysis of the quantitative data and discussions with key informants. The schedule was developed to guide the course of the interview, provide default forms of asking questions, and to ensure that all topics of interest were covered. The interviews were conducted like a conversation, in an open, free-flowing and flexible manner. The interview schedule was not designed to be proscriptive. The interview began by asking the participant about their background, current living arrangements, employment, education and social
networks. These questions were asked partly to gain this information but also to further develop rapport and help elicit less guarded, more personal, responses to questions later in the interview. Young people were then questioned about their general health; what it is like now, how it has changed over time, and how they look after their health. The interview then focused more specifically on hepatitis C testing and their experience(s) of being tested.

Table 23. Schedule of questions for semi-structure interviews

<table>
<thead>
<tr>
<th>Question</th>
<th>Probes</th>
</tr>
</thead>
<tbody>
<tr>
<td>In this interview I would like to talk with you a bit about your overall health and well-being, in particular things that may affect it, how you think about it, what you do about it and if it has changed over time.</td>
<td></td>
</tr>
<tr>
<td>I would like to start though by asking you a couple of questions about yourself, to get a sense of what’s happening for you and how life is for you at the moment.</td>
<td></td>
</tr>
<tr>
<td>1. Can you tell me what you are doing now:</td>
<td>- Living situation?</td>
</tr>
<tr>
<td>where you’re living and how you spend your time?</td>
<td>- How do you spend time?</td>
</tr>
<tr>
<td>2. How would you describe your health now?</td>
<td>- Do you think about it?</td>
</tr>
<tr>
<td>- What sort things make you think about it?</td>
<td>- When was the last time you thought about it? What were you doing? i.e.</td>
</tr>
<tr>
<td>- physical activities, food, drugs, sex</td>
<td></td>
</tr>
<tr>
<td>3. Has your health changed over time? Can you tell me about that?</td>
<td>- What sorts of things affect your health?</td>
</tr>
<tr>
<td>- What were you doing? i.e. physical activities, food, drugs, sex</td>
<td>- Tell me about the last time you were sick? What happened?</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>
4. **What do you do if you are concerned about your health?**
   - What did you do? Who did you see?
   - When would you do to a doctor or health professional?
   - Did you do things differently before you first left home?
   - Have you always done this?

**Now I would like to ask you some questions about some medical tests that you may have had and your experiences of having those tests**

5. **What have you been tested for?**
   - e.g. HIV, STI’s, Hepatitis C

6. **Can you tell me about the first time you were tested for hepatitis C?**
   - What happened?
   - What made/prompted you want to have the test?
   - Where were you? Who tested you?
   - How did they test you?
   - Were you also tested for other things?
   - How were you feeling?
   - What happened afterwards?
   - Did that time differ from other times? How so? What happened?

7. **Can you tell me about when you found out about the results of these tests?**
   - What happened? Where were you?
   - Who told you? What did they tell you? What support was offered?
   - How were you feeling?
   - What happened afterwards?

8. **How did you feel about the way you were tested? What was good/bad about it?**
   - What was the experience like? - good, bad, scary? What was good about it?
   - What could have been better?
   - Did you feel supported?

9. **Since you were told your test result have you been doing anything differently?**
   - Have things changed?
   - What sought of things? e.g. eating, drinking, drugs, sharing, sex, using services, life philosophy, job?
   - Are things easier or harder?

10. **Have there been any times when you wanted to have a hepatitis C test but did not? Can you tell me about that/those?**
    - What happened?
    - Where were you going to go?
    - What made/prompted you want to
11. What is your understanding of hepatitis C?
- When did you first hear about it?
- What have you heard about it? What were you doing?
- Do you think it will/could affect your life? In what way?

12. Can you tell me about services you have used in the past for health issues or problems? What about for hepatitis C issues? What was your experience of those services?
- Where did you go?
- Who do you see?
- What did they do with you/for you?
- Was it helpful/unhelpful? Did it meet your needs/wants?
- Did you receive treatment?
- How did you feel? understood? comfortable?
- Have there been times when you wanted help but did not seek help? What prevented you from seeking help?
- What sort of services want you like to see?
- What would make the services better?

The participants were not informed that the interviewer had prior knowledge that they had been tested for hepatitis C but, rather, this was allowed to emerge during the course of the interview. This approach was preferred over a more direct approach, as it may have been intimidating for the participant to have previous responses to surveys presented to them and may have impeded the development of rapport.
The interview was recoded on minidisk (digital recording) and later transferred to audiotape for transcription. The interviews ran for an average of 37 minutes and ranged from 25 to 48 minutes. The interviews were conducted at either the Key Centre for Women’s Health in Society or another allied research centre. At the end of the interview, participants were thanked for their time, debriefed and given $25 compensation. Payments were made to reimburse young people for time and because they had also received payment for their participation in the longitudinal surveys.

4.2. Data Analysis

The digital recordings of interviews with young people were transcribed by a professional transcriber shortly after the interview occurred (within approximately 2 weeks). The transcripts were thoroughly checked by the author for quality, which involved listening to the digital recording while reading the transcript and correcting all errors and omissions. The relatively rapid conversion of audio to text enabled fieldwork and analysis to be a dynamic process.

The analysis of interview data was primarily thematic and focused on the reasons why young people were tested for hepatitis C and the ideas that informed these reasons. Preliminary analysis began shortly after the first interview was completed, although fine-grade analysis was not performed until after all the interviews had been completed. Analysis of interview data began early in the collection process, in part, to ascertain whether all the salient issues relating to reasons for hepatitis C testing, for these young people, had been uncovered. This is known as “saturation” and refers to the point in sampling when no further insight into the issue being explored – in this case the reasons for hepatitis C testing – could be achieved through further sampling (Dempsey, 2006; Strauss & Corbin, 1990). Although the number of interviews for this study was predetermined to a large degree before fieldwork commencement, the preliminary analysis provided grounds from which to make a judgement as to whether saturation had been reached. If it was apparent that it had not been achieved, additional interviews could have been completed. It was obvious by interview 16/17 however, that saturation had been achieved.
The process of analysis involved reading and re-reading the transcripts until common themes or ideas emerged. Notes were made in the margins of printed copies of transcripts. A case summary for each interview was also prepared that summarised the young person’s current situation, health status, approach to health management, accounts of hepatitis C testing, hepatitis C knowledge, and service utilisation. The summaries also included responses to longitudinal survey items relating to these factors and overarching themes that would aid in understanding how the young person interpreted and responded to their world. Tentative findings were thoroughly explored within and between interviews to fully determine their plausibility and explore nuance. Qualitative data analysis software (e.g. NVivo or Atlas.ti) was not used in the analysis of these data as, in the authors experience, such applications are relatively cumbersome to use and can actually prevent the researcher from adequately understanding data. This is particularly true for studies with a relatively small number of participants, as was the case for this research.

Following the analysis, concise case studies were written of four young people – one for each major theme – and are used in the results section to bring-to-life the themes, as well as, provide a basis from which to discuss each theme. Verbatim extracts as also used from all interviews to further facilitate discussion of the themes. The extracts cited in the results section use the following notation: I = Interviewer; R = Respondent. The page and line numbers, which encompass the extract, are also noted (e.g. 10/4-12 indicates the extract is from page 10 of the transcript and begins at line four and ends on line 12).

In describing the analytical strategy adopted in the study, it is also important to discuss the claims to knowledge this process can make regarding the reasons young people who experience homelessness are tested for hepatitis C. This thesis holds there is an objective reality and that research methodology provides a means of tapping into or seeing this reality. Different methods – whether qualitative or quantitative – simply provide different ways of understanding or knowing phenomenon. Neither is more creditable, more real or more accurate than the other.
This study focuses on the language used by young people who experience homelessness to express their experiences of hepatitis C testing. The language used by individuals can “convey experience grounded in objective reality” (Dempsey, 2006, p.98); it provides a window into how people interpret and respond to the external world. This is not to underestimate or minimise however, the explicit or implicit influence the research process – itself interpretative – or personally-held values and experiences of the researcher can exert on the participant. To overcome these issues the interviews were conducted in a manner that ensured care was taken to listen to the way young people expressed their own stories and specific words they used (e.g. risk and related words). In the case of the latter, care was also taken to explore the young people’s personal interpretation of these words and ideas.

It is not a claim of this study that findings will necessarily be representative of or generalise to the broader population of young people who experience homelessness in a statistical sense. Semi-structured qualitative interviewing is used in this study because it is the process, meaning and experience of testing that is of interest, not the amount, quantity, intensity or frequency of testing (Denzin & Lincoln, 2000). The aim of this study is to document and examine the detail contained in young people’s stories of hepatitis C testing and to reflect the diversity of these experiences. The loss of generalisability inherent in the use of qualitative methodology is compensated through the richness of the data and the inferred meaning (Keogh, 2003). Moreover, through employing a sampling frame based on principles of diversity, rather than probabilistic notions of representativeness, and having confidence that saturation had been achieved, the findings of this study can be presumed to plausibly reflect the range of reasons young people who experience homelessness in Melbourne are tested for hepatitis C.

4.3. Results

The young people interviewed in this study were very willing to talk at length about themselves, their health and their experience(s) of hepatitis C testing. They appeared open and honest in their responses to questions and spontaneously recounted highly
personal and sensitive experiences, such as those relating to drug use and sexual relationships. This openness was partly due to the time taken to develop rapport before the interview but also due to their previous research participation. More, specifically, the young people in this sample had completed a number of surveys and semi-structured interviews of varying lengths as part of Project i and typically reported a positive experience from their participation.

The interview schedule was designed to openly question young people about hepatitis C testing however, it was apparent that for many young people hepatitis C testing was a salient issue. Many young people spontaneously spoke about hepatitis C and other blood-borne virus testing when asked about their health. Brian, for example, when asked to describe his health said:

R: Yeah, just a normal bill of health I suppose, yeah,
I: Like, that’s good or bad or?
R: Yeah, I’m HIV negative, Hep C negative or whatever you call it, all that negative and, yeah … (4/25-33).

For other young people however, hepatitis C testing was a less immediate issue and they only spoke about their testing experiences after direct probing and questioning.

The majority of the young people in this sample had been tested for hepatitis C more than once in their lifetime. Eleven of the twenty young people had been tested between two and four times, while six young people described being tested five or more times, some as many as four times a year for the past five years. Only three young people had been tested for hepatitis C on only one occasion.

The analysis of the interviews with young people focused on the reasons given as to why they were tested for hepatitis C. Four major themes emerged: “danger”, “safety”, “trust” and “circumstance”. Although these themes will be discussed separately, they were not mutually exclusive but reflected the different ways in which young people sought or received hepatitis C testing. Furthermore, the reasons given for why they were
tested and the ideas that informed these reasons were not always the same each time they were tested. Three of the themes – danger, safety and trust – reflected three different ways in which young people positioned themselves as active and conscious decision-makers in relation to hepatitis C testing. The young people in these groups identified their own need for testing and, subsequently, actively sought out a health service. The fourth theme – circumstance – reflected the way in which many young people did not actively seek testing or identify a need to be tested but rather, were only tested because of a situation or context in which they found themselves.
Frank was 19 years old and lived with his parents and brother. He had moved in and out of his parent’s home many times, mostly because he “gets kicked out”. During his times out of home he had generally lived with friends but sometimes stayed at a refuge. He also once lived on the street. He was completing Year 11 equivalent at TAFE and hoped to start a graphic design or architecture course, after finishing Year 12 next year. Frank received the Youth Allowance from Centrelink. He also had a 17-month-old son who does not live with him.

Frank’s health was relatively poor. He said he is very unfit and does not eat very well. He thought about his health a lot, particularly his weight, but did not describe ways he had tried to change the situation. Frank was also quite depressed and had thought about suicide several times. He said, however, that the thought of his son has prevented him from attempting suicide.

Frank had twice been tested for hepatitis C. The first time was shortly after he and a friend had bought some speed together. They wanted to inject it but only had one needle. At the time, Frank was not concerned about sharing the needle with his friend, as he had known him all his life and knew (or at least believed) he was disease free. A few days later, however, he started to experience liver pains and became very worried he had caught something. He went to a health service for injecting drug users in inner Melbourne and asked to be tested because he was worried. Frank said he was tested for “everything”, which he remembers including AIDS and hepatitis A, B and C. Frank was very relieved that he had actually sought testing and happy that the staff were relaxed and supportive. Despite this, he was very nervous while waiting for the results. The test results were negative.

The second time Frank was tested was after he had started injecting again shortly after being thrown out of home again. He was living with two injecting drug users and become worried that he had caught something because he was getting easily drunk again, which he believed is a sign of hepatitis C. He was worried in spite of the fact that he had not shared needles since starting again and had not allow anyone else to touch his injecting equipment. The test results were again negative.
Frank’s story illustrates what many young people recounted in their reasons for being tested for hepatitis C. These young people reported engaging in a practice or being in a situation, which they believed had put them in danger of contracting hepatitis C. Feeling worried after this event, they sought testing at a health service. They had made a choice to be tested based upon a perceived danger, which in this context refers to a practice or situation that caused them to become concerned about their health and well-being. As such, it was a practice or situation they deemed personally dangerous or threatening. This was the most commonly occurring theme, with eleven (8 female, 3 male) of the twenty young people interviewed having stories that included the idea of danger.

Like Frank, a small number of young people believed that they had been experiencing symptoms of hepatitis C or another infection, as a direct result of the danger they had experienced. The majority, however, did not display observable symptoms and were primarily concerned about the perceived probability that they had contracted hepatitis C and another infection. Young people were often highly anxious leading up to the test, however the decision to test and subsequent testing often brought young people relief. As may be expected, anxiety about a possible positive result built before they received their test results and receded when a negative result was received.

Although all of these young people chose to be tested, the length of time between experiencing perceived danger and testing varied. Some, after engaging in practices that caused them to become highly concerned, had sought out testing within a short period of time, generally, a few days or up to a week later. For others, however, it was clear that testing was sought some time after the event or events had occurred, ranging from at least several weeks to several months. The latter group chose to be tested only after experiencing the danger multiple times, for example, unprotected sex with a number of people over a period of time. Although there is insufficient questioning about this facet of testing to thoroughly explore this idea in detail, it is likely that, for these young people, engaging in a danger only once may be insufficient to generate enough concern for them to feel they needed to be tested.
Two sub-themes – “active danger” and “exposure” – emerged from the stories of young people who had a danger account for testing. These sub-themes related to the way young people positioned themselves in relation to the danger, as either active participants, if not instigators, or as passive recipients.

4.3.1.1. Active Danger

Most young people positioned themselves as active participants in the danger or practice that caused them to seek hepatitis C testing. They were in control and made a choice to engage in the danger. The dangerous practices described by young people within this sub-theme are typically constructed as risk practices within the health and social sciences. Risk however, is a problematic label given the myriad of meanings that are attached to the term within these disciplines and is intentionally not used here for two main reasons. First, when some health practitioners, researchers and policy makers employ this term, they implicitly blame the individual for their engagement in certain practices or circumstance (Lupton, 1993). As such, young people who engage in these specific practices are presumed to knowingly put themselves at risk or seek out risk. This is seen as their motivating reason for their actions and why they are morally held to account. Second, and more importantly, the majority of the young people interviewed here did not use the word ‘risk’ to describe or label their practices.

The dangers in which young people actively engaged centred on two practices: injecting drugs and sex. Three young people, including Frank, identified sharing needles and/or equipment while injecting drugs, as the practices that prompted them to seek testing. Frank explicitly recounted how he and a friend injected amphetamines together using the same needle. Frank knew what he was doing was potentially harmful but disregarded his knowledge at that point in time because his desire for speed outweighed any concerns he may have had about the potential health consequences of sharing needles. It was only after a couple of days had passed that he started to think about what had happened and become concerned. In fact later in the interview, when asked about his understanding of hepatitis C, Frank revealed the extent of his awareness of the possibility of contracting hepatitis C though sharing needles.
Injecting for Frank opens up the possibility of getting “someone else’s fucked up disease”. The disease comes from others – they had it first – and, implicitly, was contracted as a consequence of their dangerous acts. These competing positions taken by Frank in relation to responsibility for the danger are reflected in at least three other interviews with other young people. For example, Shannon – a 20-year-old woman – told how she went to be tested for hepatitis C and other blood-borne viruses because she had been “… kissing people and stuff and you know, stuff like that I was just concerned just ‘cause I don’t know them sort of thing, so just -- yeah, worried about my health ... (12/3-5)”. She then went on to say:

\[ R: \text{And I was -- yeah a few boys living there [a youth refuge] and stuff} \]
\[ \text{that didn’t really look after themselves, so I, you know, I was a bit wary} \]
\[ \text{living with them,} \]
\[ I: \text{How do you mean like looking after themselves like what sort of things} \]
\[ \text{were they doing?} \]
\[ R: \text{Oh, like just chroming and like just -- yeah, young stupid things} \]
\[ (12/20-34). \]

Although Shannon actively participated in the practices – kissing and “stuff” – she identified as the reason why she sought hepatitis C testing, she also implied in her statement a belief that these practices were rendered dangerous only because the boys were “stupid” and “young”. For these reasons she was wary of them. To Shannon, these boys were contaminated and, therefore, contact with them was dangerous.
The two young women also in this grouping described a series of events rather than one specific episode of needle sharing. Naomi, who was hepatitis C positive at the time of the interview, said that one of the times she was tested for hepatitis C was when she had gone to a clinic because she believed she had a sexually transmitted infection. When she arrived at the clinic Naomi asked to be tested for “everything” – including hepatitis C and HIV – because she had injected drugs and had shared needles and equipment a few times.

_I_: Yeah -- was it something -- like how did you get onto having the Hep C and HIV test? Is it something they suggested? Did you ask for it?

_R_: Oh, no, I asked for it, I, I just said can I please have um, a full test for everything, HIV, Hep C, Hep B, Hep A.

_I_: Did they ask any questions about why you wanted that or?

_R_: Yeah, she just asked specifically just like that “why would you like this done?” and I said “because I’m an intravenous drug user and I inject and I’ve, I’ve shared, I’ve shared needles a few times and shared the same spoons and the same equipment … (13/26-37).

For Naomi, there is a clear hierarchy to the dangerous practices in which she had engaged. First, she injected drugs, and second, she shared needles and other injecting related equipment with other people. Although Naomi goes on to say that at the time she “didn’t really know much about hepatitis C (14/5-6)” she obviously understood that injecting and sharing while injecting were dangerous. She also said she “had a real strong suspicion it was going to come back positive (14/18-19)”, mostly because her boyfriend of the time had also tested positive.

The second young woman, Claire, also saw being a “drug user” (which from other sections of her interview meant injecting heroin) and “sharing” as the reason for going to a doctor for blood tests. When asked how many times she had been tested for hepatitis C Claire said:
R: Oh, gee I’ve had quite a few blood tests since I’ve been a drug user, that is actually things I’ve gone -- I didn’t think of that, to the doctor for.
I: Maybe you can tell me a bit about that then …
R: I don’t know, just like when you thought maybe you expose yourself to a risk,
I: In -- what do you mean by risk?
R: Like, sharing [pause 2 secs] someone sharing, just [pause 2 secs] …
(7/50-8/4)

The specifics of “sharing” were not captured, as Claire goes on to recount how she was exposed to someone else’s blood through a first aid situation and does not return to the topic of sharing. However, within the context of her account it seems quite likely that “sharing” refers to sharing needles and/or other injecting equipment. Interestingly, Claire is also one of two young people who explicitly used the word ‘risk’ and linked it directly to these practices. Later in the interview when asked about the reasons she had been tested on other occasions, Claire said:

… basically just because I’ve been worried for myself and things like maybe I put myself at a bit of risk or something (10/12-14).

Claire used the term risk in a conventional way and suggests she was at risk because she chose to expose herself to something that was dangerous. Another young woman – Ester – spoke about risk but did so only within the context of retelling another’s words. Ester, in retelling the conversation she had with a nurse when she was tested for hepatitis C for the second time, said:

… I think she actually said if you’ve ever done anything, like even just share razor blades with friends, then, then you could be at risk …
(16/37-39).

In this retelling, Ester used risk in an unusual way. She described sharing as an action that leads to a state of being “at-risk” rather than sharing being a risk practice or placing
you at-risk of contracting hepatitis C. Rather than the contemplating or doing of practices which in and of themselves are risky, the emphasis is on the after effect or consequence of this practice that leads to being at-risk. In this context, at-risk seems to mean it is unknown whether they have hepatitis C or not and is, perhaps, why testing can stop you from being at-risk.

The majority of young people however, did not use the term risk to label their practices. They did not go out to put themselves at-risk. Instead they used terms that described a psychological or emotional reaction to the danger they had experienced. Luke, for example, said he went to the doctor to get tested after he had a “scare”, which for him was having sex with someone who later said they were hepatitis B positive. Ester and Amber, on the other hand, talked about being “paranoid” after having unprotected sex. Other young people simply stated they were concerned or worried after having engaged in particular practices. The term used by Holly was slightly different from all other young people. Holly referred to her practices that caused her to want to be tested, namely unprotected sex, as “mistakes”. When asked if she had done anything differently since having the tests Holly replied:

Amazingly enough I don’t learn from my mistakes [laughs] but, yeah, I don’t know, the [pause 2 secs] I try to do things differently but -- and I’ve got a very one tracked mind [laughs] like my mind’s thinking about one thing, it just doesn’t think about another thing, yeah (15/14-17).

Holly initially sought testing because of a mistake and repeatedly sought testing because she kept making mistakes. In contrast to other young people, she is also, in the extract above, making a moral judgement on her behaviour; what she had done, according to her, was a mistake and wrong. Implied in all of the different terms used by young people, is the knowledge that engaging in particular practices or situations potentially had placed them in danger and that they are unhappy with the potential consequences.

The second category of dangerous practices described by young people in their stories about testing was sexual practices; seven young people identified these practices in their
story. The majority described situations in which they had a “one-night stand” – having sex with someone with whom they had no intention of seeing again – and not using barrier protection (i.e. condoms). Holly, for example, said she used to “play around” when she was younger. She said she had unprotected sex with different people, usually while affected by alcohol and/or marijuana and, as a consequence, wanted to be tested. It was not a single episode of unprotected sex that prompted her to seek testing, but rather, the repeated engagement in unprotected sex. In a similar story, Brian said that the first time he was tested was because he had unprotected sex with several girls in a few months.

*I: Maybe you could tell me a bit about the first time that you, you went to get tested?*
*R: Yeah the first time I got tested,*
*I: Why, why and where you went and?*
*R: It was ‘cause I’d been with, like about two or three chicks or four chicks, like it was for like four months -- three months or four months and ended up having unprotected sex, or -- and like there was a part there where I did go for unprotected sex for a little while, just in general, you know (5/27-37).*

Unprotected sex was not always a feature of the sexual practices described by young people. Ester, in her recounting of the two times she was been tested for hepatitis C, says she sought to be tested after having sex with someone she met in a club. She sought testing even though they had used condoms. She says, “… yeah, it’s not like a hundred percent. You know I just was paranoid, I guess, I didn’t want to catch anything from him” (11/38-39). Later in the interview she also said, “I’m really careful with all of that stuff and even if I do anything and I’m careful, I’m still worried about it anyway [laughs]” (15/58-60). For Ester, this paranoia and worry stemmed from her religious schooling and upbringing where she was taught that sexual transmitted diseases were God’s punishment for having sex outside marriage.
4.3.1.2. Exposure: Passive Danger

Exposure was the second idea to emerge within the theme of danger. It was a much less common idea than active danger and was apparent in the stories of only two young women. These young women positioned themselves as passive recipients in their experience of danger. They did not initiate the danger or choose to participate in the danger; it was out of their control. They did, however, choose to alleviate the concern they felt from being exposed to a specific perceived danger by seeking testing.

The dangers these young women were exposed to were different to the dangers present in the stories of young people that centred on active danger. Lesley, a 20-year-old hairdressing apprentice for example, first sought testing because she had cut her hand on a glass that a customer had been drinking from while working. She was advised by her employer to seek testing and became very concerned about the possibility that she had contracted something from the customer. The second young woman – Amy – was also 20 years old at the time of the interview and spent the majority of her day looking after her two daughters. She recounted that the first time she was tested for hepatitis C was when she was living in a refuge for young people who experience homelessness. She recalled that one of the young people also staying in the refuge was found to be hepatitis C positive. She said:

> But like, I thought maybe I should just go get, get myself tested, you know, just in case, because there was people at the refuge that I was staying at that had Hep C and stuff, so I thought maybe I should get myself checked out (10/26-37).

Amy believed she may have been at danger of contracting hepatitis C because the staff working in the refuge suggested it could be caught through sharing “cups and stuff” (10/59). Amy said that everyone in the refuge became very concerned and, although she does not recount in her story having felt this herself, thought she should be tested to see if she was “okay”.
4.3.2. Safety

Amber

Amber was 21 years old and at the time of the interview had been living with her boyfriend at his family’s home for little more than a month. Prior to this she had been living with her aunt for some time but had to leave because they had an argument. She felt very uncomfortable living at her boyfriend’s family home – it “isn’t homey” to her – and was in the process of moving out with a friend. Amber supported herself by working two jobs.

Amber’s health was good. She thought a lot more about her health than she once did and described it as her future. She had not been sick in a long time and felt a lot better since starting work again. When she had not been working she had very little motivation to do anything and would sleep for the majority of the day. Amber had recently started boxing/personal training to keep fit. She loved this form of exercise because, for her, it kept her physically and mentally fit.

Amber was first tested for hepatitis C when she was 15 years old. She wanted to be tested because she had had several different sexual partners – one-night stands – and had not always used condoms. She went to her doctor and simply asked for a blood test. The doctor asked why she wanted a blood test to which she replied, “to see if everything is okay” and proceeded to tell the doctor told about her partners. She had been very scared during the process, as she was convinced she would have something. Amber received the results via mail a couple of weeks later and was incredibly relieved to find they were negative.

Since this first time, Amber has had her bloods done approximately every six months. She is unsure precisely what she is tested for – she just gets them all done – but says it includes HIV, STIs, hepatitis B and C and few others. She gets them done just for general health reasons and because it is “better [to] be safe than sorry”. She has not had many different partners but believes “you never know” and that you “could sit in a toilet seat and get something”. She says that she was not as scared about being tested as the first time. This is mostly because she believes she was not in danger.
Amber’s story illustrates the second major theme – safety – that emerged from the reasons why a small group of young people sought hepatitis C testing. Their testing stories typically began like those discussed under the theme of danger. Amber first sought testing because she had engaged in unprotected sex a number of times. The difference between Amber’s story and those described in the previous theme however, were her subsequent actions. She chose to continue to seek testing despite not having engaged in specific practices or having been in specific situations that she perceived to be dangerous. She indicated it was a way of keeping herself safe and looking after or managing her health. Four young people (2 female, 2 male), including Amber, recounted similar stories.

Hepatitis C testing, for these young people, was a routine practice or habit. They were tested because of the threat of hepatitis C rather than because of a risk practice. They reported having been tested for hepatitis C, as well as other blood-borne viruses and sexually transmitted infections, many times over their lifetime and at regular intervals, generally every three to six months. They generally described their pattern of testing in a matter-of-fact manner. Lesley, who has been tested up to twenty times over a five-year period said, “Yeah, it’s just habit. I’ve got a habit of just going and getting tested” (8/27-28). Brain, who had been tested for hepatitis C approximately nine times, talked about it in a similar manner to Lesley, he said, “… I generally get tested every three to six months anyway just out of, you know, it’s just a thing I do” (4/41-41). A little later in the interview when asked if there were differences between the first time he had been tested for hepatitis C and subsequent times, Brain said:

Oh, they weren’t as strenuous, it more became routine, well to me more to the point, so, it wasn’t really anything in any way, it was just like “oh, yeah, time to get tested again”, yep, book -- make a booking, go to the doctor, yeah (9/6-9).

Brain’s suggestion that testing had become a much less stressful experience because it has become routine is reflected in many of the other interviews. Hepatitis C testing for these young people had moved from being a scary new experience to a standard practice
that generated little anxiety. This is not to suggest that these young people were devoid of all anxiety during the process of being tested, as some did report feeling worried particularly when receiving the test results but, rather, that through regularly experiencing the process of being tested they found it considerably less stressful.

Young people expressed the reasons why they regularly sought testing in several ways. Some young people suggested they were tested for hepatitis C because they wanted “just to be sure” they did not have it, while others, like Brain and Daryl, talked about being tested for “peace of mind”. The most common way, however, was to directly use the word “safe”, for example being tested “just to keep meself safe”. The different ways young people talked about their pattern of testing implies that testing is used to give themselves the feeling of being safe through confirming they were infection free, despite not actually specifically experiencing a perceived danger.

Lesley, for example, who repeatedly used the word “safe” over the course of her interview recounted that testing is about “just to make sure it’s all safe” and “getting the all-clear”. When asked “how did you feel about the way you were tested?” she replied:

\[ \text{R: I felt fine (was it good or bad?), I didn’t like the part where the needle was jabbed in my arm ... but hey, the blood’s taken, I get the test results, they go, it’s all clear. It’s like okay.} \]

\[ \text{I: Yeah. Wh, and that was the good stuff about it, were the any other good parts about it? Like, that you’re happy with.} \]

\[ \text{R: Hey, the results always come back fine (13/39-14/4).} \]

The possibility of a positive test result seems not to be her expected outcome.

The seed for this pattern of testing seems to originate from the doctor who first tested Lesley. She said the doctor suggested that because she worked in “food industries and industries with people” (9/10) she “should just always get tested every few months” (9/10-11) because “it’ll be safer” (8/44). The adoption of the doctor’s advice contrasted to her general view on doctors and the way she managed her health more generally.
During the interview Lesley described doctors as “a heap of quacks” (6/15) and avoids them “at all costs” (6/11). If she did see a doctor, she is “just zoned out” (14/10-11) and does not listen to them. Furthermore, when asked what she would like to hear from doctors, she said “I wouldn’t listen to them anyway” (14/16). The advice to regular test however, seems to have struck a chord with Lesley and activated her into a pattern of testing. Although it is unclear from the interview why this is the case, a clue perhaps lies in her perception of the infection(s) she believed she could catch. When asked who she would have told in the event of a positive result. She replied:

_Nah, I’d only tell who ever needed to know. It’s all, like you don’t just go around telling anyone that kind of stuff because like, people, like err hex [laughs] (12/39-41)._

To Lesley, such infections are bad – “hex” – and not to be mentioned to others, presumably, because of the stigma she believed is associated with such infections or disease. Daryl told a similar story of adopting a doctor’s advice to regularly test for hepatitis C, however, this was not evident in the story of the other two young people in this grouping.

Linked to the idea of getting tested to keep safe is a desire of “not wanting to be sorry”. These young people stated several times during their interview that they regularly sought testing because they would “rather be safe than sorry”. For these young people, “not wanting to be sorry” seemed to reflect a belief that it was better to know about any previously unknown infection now rather, than to find out some time in future. Most of these four young people expressed a fear of discovering in years to come that they had an infection or disease which they had for some time. Lesley, for example, said:

_Like I don’t want to walk around with HIV for like 10 years and never find out (yeah) hey you’ve had HIV for 10 years. It’s like, get tested be safe (8/28-30)._
Although Lesley refers to HIV in this extract, hepatitis C and B were also part of her testing regime. In this extract, Lesley’s concern centres on herself; she would hate to discover she had an infection or disease which she views as “horrible”. Daryl is also concerned about the possibility of not knowing he had an infection or disease. His concern, unlike Lesley’s however, is about the potential to give someone else an infection. When asked about “the reasons why you go now like -- and keep going”, Daryl said:

*Just to make sure. Just if there hasn’t been something that they haven’t detected in say years just -- I, I just need to know because I’d hate to have something like that and give it to someone else, it’s just not right …*  

*(11/41-43)*

For Daryl, it is just “not right” to give someone an infection or disease, especially if he thought he did not have an infection or disease. Through this statement he assumed the responsibility of making others safe by knowing at all times the current state of his health, in terms of infections and diseases. Interestingly, Daryl’s position also seems to suggest that it is not shared practices that would cause him to “give it to someone” but, rather, his negligence in not knowing he carried an infection or disease.

Embedded in the idea of safety for these young people was also an idea of danger. This danger is different to that discussed in the previous theme, as it is pervasive and unavoidable and not linked to a specific practice or situation. No matter how hard they tried to avoid perceived danger there was still the possibility that they could contract a blood-borne virus or sexually transmissible infection. Amber, for example, after suggesting she had not sought hepatitis C testing, on most occasions, as a consequence of experiencing a danger, said:

*… you never know. I mean, I mean you can sit on a toilet and get something, sort of thing, so, it’s just -- yeah, I guess it’s my paranoia [laughter] (12/55-57).*
Although Amber joked about being “paranoid” she is presumably serious in her assertions, as she offers no other reasons for why she has sought hepatitis C testing on many occasions.

Some of the young people in this grouping reported taking steps or measures to protect themselves against perceived dangers but still believed in the possibility that “something could happen”. These preventive measures were for specific known perceived dangers. Daryl, who regularly injected amphetamines, for example, described practices that he believed kept him safe while injecting. These practices entailed using a clean needle every time he injected and placing it in a needle bin when he had finished. However, despite being “like the most careful at times” (12/7) he said, “accidents still can happen” (12/7-8).
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**David**

David was 21 years old and lived in a share house with two other men. He was relatively unhappy with this arrangement and is looking forward to the day when he can live by himself. After having to leave home, David lived with a friend for a short time. He then went to a youth refuge and then entered transitional housing. David was working full-time at a butcher’s shop and when not working he spent much of the time by himself.

David’s health was not as good as it has been. Two years ago David damaged his back in a motor vehicle accident, which was also the catalyst for his homelessness. Although David says the accident had not really affected him, he was unable to continue working as a forklift driver and had seen a doctor for related issues at least six times in the past few months.

David had twice been tested for hepatitis C. The first time was when he was 16 years old. He had a steady girlfriend and wanted to make sure everything was okay. They briefly discussed having testing and then simply went to have it done. David said it was “a commonsense sort of thing”. They went to a general practitioner and asked to be tested for as many STDs as possible. David said that the doctor didn’t ask many questions but gave them a little spiel about protection, which they were already using, and other things. David returned to the doctor a couple of weeks later for his results. The doctor simply gave him the results and said “don’t worry about it, everything is fine, keep doing what you are doing”. The appointment took only 5 minutes. In hindsight he was unsure exactly what he was tested for; he had not take much notice, as he was just glad for the results.

The second time David was tested was when he was 18 years old. He had a new girlfriend who had not previously had sex and “didn’t want anything to go wrong”. David said he was tested mostly for her sake – “it was an emotional thing” – but was also interested in the result for himself, as there had been a few events in the past that caused him to think he might been exposed, such as having unprotected sex and living in a youth refuge with someone who had hepatitis (either B or C). The results came back negative.
David’s story illustrates what six young people (3 female, 3 male) recounted in their reasons for being tested for hepatitis C. These young people, like those described within the previous themes, made a choice to be tested for hepatitis C and other blood-borne viruses. However unlike the young people within the previous themes, testing primarily served a social rather than a personal or medical function. They chose to be tested because of issues of trust that arose between themselves and their sexual partner. Although ideas of danger and exposure are evident in these stories, the emphasis of their reasons for testing centred on issues of trust. The idea of trust was invoked in two distinct ways in these stories. First, testing was a way to build trust with their sexual partner and second, testing was sought after trust had been broken.

4.3.3.1. Building Trust

Four young people described situations in which they used hepatitis C testing as a way of building trust with their partner in newly formed sexual relationships. Some described situations where testing was sought before sexual contact had begun, however for others, sexual contact had already begun and it was implied that testing was for the purpose of discontinuing condom use. These young people believed that having sex, particularly unprotected sex, was a practice that could lead to contracting infections from other people. Testing provided an external guarantee that they were clean and would not pose a danger to their partner. It also provided a point from which they could engage in a practice they believed could be dangerous. Implied also is the assumption that they, and their partner would remain infection free and not engage in practices that could expose each other to danger. Rather than indicating mistrust in each other, testing for these young people was a marker or demonstration of commitment and openness with each other.

Archie, for example, was 18 years old and had been tested for hepatitis C three times over his lifetime. He wanted to be tested because he and his girlfriend were “getting intimate”. It was also the first time he had freely chosen to be tested. He said:
Yeah, so I’d always kept pretty clean when it come to drugs and stuff like that so I never really worried about me blood line, I always knew I’d, you know, be clean, but when we got together I started realising that yeah, you know, all it takes, is um, a cut in your arm and the wind to brush past, you know, someone’s got Hep C or something, you know, well I just started peaking about stuff like that ‘cause I was with her and we were getting intimate, we were touching each other in places, you know, that could swap diseases if either of us had ‘em, so, that’s what made me really stress, when up for my blood test and everything (6/6-18).

The need to know he was “clean” was very important to Archie. Although expressed in different ways, this need was reflected in all of the interviews with young people in this grouping. The other young people spoke about wanting to know they were “safe” or “okay” so that that both parties did not have to worry these issues in the future. Archie’s concern about the possibility of “swapping diseases” with his girlfriend was despite describing measures he had taken to ensure he remained clean, such as not sharing needles when he injected drugs and obtaining his needles, swabs, spoon and water from a needle and syringe exchange program. Being tested, however, provided him with certainty.

The stories of these young people also reflected a strong sense of ownership or responsibility for their own health status and the consequences their actions or health status may have for other people. David, for example, when talking about the why he was tested for hepatitis C for the first time said, “… you know, I obviously just wanted to make sure that there was nothing, wrong um, and we both went and got tested” (9/50-53), and a little later in the interview, that it was “… just sort of fear of, you know, contracting anything or passing anything along, not wanting to obviously be a bearer of something” (10/12-14). David was, in part, attempting to protect his girlfriend from possible danger.
One young man described how testing for hepatitis C and other blood-borne viruses had become a standard policy in newly formed relationships. He was first tested for hepatitis C because he had unprotected sex with several young women over a few months however, since then he consciously used condoms “a lot more” in relationships. He continued to use condoms until he felt he knew the person and they had both undergone the tests. He said:

*R: I'm making it like a standard thing now. I mean like I’ve had -- you know, I’ve had a few chicks that have been weirded out and ran off sort of speak, you know, but,

*I: Because you’d asked them?

*R: Because I’ve asked them “look could you get tested before, you know [laughs]” and -- but a lot of other chicks have been really cool with it and stuff so. Yeah, ‘cause I’ve had ones that aren’t cool that obviously just may have something to hide [laughs] don’t know (8/48-61).

In addition to wanting to ensure that he and his partner were safe, testing for Brain had also become a test of the relationship itself. To him, the willingness to have a test demonstrated openness, while unwillingness to have the test demonstrated a lack of openness in the relationship and that there was potentially something to hide.

4.3.3.2. Breaking Trust

Two young women recounted being tested for hepatitis C because of the breaking of trust implicit in their sexual relationship. In their stories, the young women described how the actions of their boyfriend caused them to believe they were now in danger of contracting an infection. Testing for these two young women was more than just alleviation of the concern they felt for their health, as described in the sub-theme exposure. It was primarily an alleviation of the anxiety they felt concerning the rupture in the trust implicit in their relationship directly caused by the actions of their partner.
These two young women recounted different dangers that lead to the rupture of the trust. Amber retold how she had been tested for hepatitis C several times in her lifetime for several different reasons. She recounted how one of the times she had been tested was after her boyfriend of the time started to inject heroin again. She said:

Yeah one time I really was just like paranoid because I was with my ex and he was a junkie and like I didn’t -- like he -- when I was with him he stopped, he wasn’t on it, and then he got back on it when he was with me...He was a junkie [laughs] and I was just like paranoid ‘cause I found like a needle in the back of his car and just all this shit and I was just like he -- we were in bed and he started -- he was whacking up, like while I was sleeping, and I woke -- that’s how I found out and I freaked out and yeah, it just -- ‘cause the needles and everything and that was just -- that’s why, ... because like he knows if he shares needles or, do you know what I mean, anything, you know, junkies they’d do anything for a hit, sort of thing so it’s like, who knows he c, could have anything really, so yeah, I was a bit paranoid about that (17/14-52).

Amber believed that she was in potential danger but not due to her own practices. She was concerned about what her boyfriend was doing – he became a “junky” – and saw that she was now potentially in danger, although exactly how is not clearly explored in the interview. It may be that she was worried about the possibility of the sexual transmission of infections he may have contracted as a result of injecting illicit drugs, as they were having unprotected sex. Alternatively, she may have been worried about possible needle stick injuries or simply being in proximity to someone who she perceived to be engaging in dangerous practices. What is clear from this account, however, is that her boyfriend’s recommencement of injecting drug use altered her assessment of the level of danger implicit in their relationship. It signalled to her that there was now a chance she could be exposed to a danger from her boyfriend where there seemingly had not been beforehand.
Scarlet, on the other hand, recounted how she sought testing after discovering that her boyfriend at the time had “cheated” on her (had sex with someone else). She said it was “not right” and that she did not trust him. She also said that she had always been a clean person and her partner’s actions caused her to question whether this was still the case. Later in the interview she said:

… if you trust someone and whatnot you’re not really worrying every week, like, you know, not, not every week, but you know what I mean, you’re not -- you haven’t got that in the back of your head or, I, I don’t really know this person, or, this is a new re -- you know (15/16-18).

Being able to trust her partner was very important and meant she did not have to constantly think about her partner’s actions. She could assume that he would not put her at danger through his actions, which clearly in this case did not happen.
4.3.4. Circumstance

Isabelle

Isabelle was 19 years old and in her first semester of a Bachelor of Arts. She had been in and out of foster care for much of her life. She has had approximately eighteen placements and had been with her current family for a little more than six months. Life had become much better for Isabelle since moving in with her newest foster family. She felt they were very inclusive and had taught her many things, such as respect, functional coping styles (for example, not using alcohol to cope when she was upset or things got too hard) and compromise, which she had not learnt because of her upbringing.

Isabelle said she used to get very sick from the stress of moving often but that her health was now a lot better than it used to be. Isabelle said she was currently experiencing a number of health issues, such as polycystic ovarian syndrome and borderline personality disorder, but that they were under control.

Isabelle had not been tested for hepatitis C for some time. The first time she was tested was after her family received a letter in the mail stating that her sister had tested positive for hepatitis C while receiving treatment at a naltrexone clinic. The letter suggested that, as a precaution, they should all be tested. Isabelle and her family went together to the naltrexone clinic be tested. Isabelle recalled the staff being friendly and that the test did not take very long. She found the experience daunting because she believed hepatitis C can be easily contracted. The clinic telephoned her father and stepmother with the results a short time later (maybe 24 hours), who in turn told Isabelle her results. The results were negative.

The second time Isabelle was tested was a follow-up test to the first. She described it as a “catch up” and said they retest again in approximately one year’s time. She was retested at the same naltrexone clinic but found her experience very different from the first time. The staff were rude to her, which she believed was because she went in by herself and was assumed to be a drug user.
Isabelle’s story illustrates what ten (6 female, 4 male) of the twenty young people interviewed recount in their reasons for being tested for hepatitis C. Their stories of hepatitis C testing were substantially different to those discussed within the previous three themes, as they position themselves as the recipients of hepatitis C testing. They had not actively sought testing for hepatitis C or identify a need to be tested but were tested for hepatitis C only because of the context or situation in which they found themselves. Furthermore, these young people were tested because of someone else’s decision, recommendation or demand.

A variety of responses to being tested were apparent among young people who were tested for this reason. The majority reported having little anxiety about being tested – it was simply a process they had to go through, albeit for different reasons.

There were three main reasons why young people were relative calm about being tested for hepatitis C. First, some young people believed they had simply not been in danger in any way. Richard, for example, when asked if he had thought about the potential results of the tests he had done, said:

*Nah, it wasn’t something playing on my mind [laughs] I knew I hadn’t put myself in a position to get any blood related diseases or sexually transmitted diseases so it wasn’t a hassle (12/54-60).*

Second, some young people reported being not worried about having testing because of other more important concerns at time they were tested. Dana, for example, was tested while having a pregnancy terminated, while Daryl was tested as part of the police response to sexual assault. Third, one young women – Jodie – stated that at the time she was tested she simply did not care that she was being tested or about the outcome of the test. Jodie recounted being unconcerned about the tests even though she clearly stated her belief that she had been at danger and even expected that she would test positive to hepatitis C.
A small number of young people who described being the recipient of testing however, did report being anxious about having the test. Their anxiety seems to stem from being asked to have a test rather than from concern about their practices or situation, as was the case for young people discussed under the theme of danger. Shannon, for example, when asked to be tested as part of a termination procedure, said it made her “worried, sort of thing, that something might be wrong” (14/52-53). She went on to say:

_I: How, how did you feel about that like?_

_R: I was a bit “well okay, well what’s wrong with me” (laughs) but no I was -- it was fine, a bit scared, but yeah, it was alright._

_I: Okay. Were there any good and -- good or bad things about the ways you’ve been tested in terms of, I don’t know things you felt could be better or?_

_R: It was bad going for it, ‘cause just thinking that I might have something, that it was good not having anything, I suppose [laughs] (15/7-17)._

The contexts in which the young people in this grouping were tested were diverse but can be grouped into four broad categories: family member was diagnosed with or previously had hepatitis C, occupational requirement, pregnancy related, and institutional requirement.

4.3.4.1. Family Member Hepatitis C Positive

Three young people, including Isabelle recounted times in which they had been tested for hepatitis C because a family member was hepatitis C positive. Isabelle retold how she was tested as a precaution because her sister had been recently diagnosed with hepatitis C while in a naltrexone clinic. It was unclear from Isabelle’s interview who within the family made the decision to actually follow-up with the advice from the clinic, however it was clear that it was not something she had previously thought about or was her decision. For Isabelle, being tested for hepatitis C was a part of other
people’s interest in her sero-status; she did not initiate testing, although she went on to say it was “a bit daunting to think that you could have it” (18/23).

Unlike others in this sub-grouping, Isabelle’s story of hepatitis C testing was very similar to the way she manages her health, or more specifically the way her health is managed by other people. Isabelle regularly consulted a number of medical practitioners for a variety of conditions. She said “there’s always little things to see the doctor about (7/7-8)”. Although she initiated the contact with doctors, the way that she described these medical interventions was as passive recipient; she was removed from the management of her conditions. It is the doctors and other health professionals who have control and make the decisions over her health, rather than herself. For example, when talking about seeing a doctor about managing polycystic ovarian syndrome, she said she is “seeing where they were going to take it” (8/7-8) and when talking about managing borderline personality disorder she said, “they’re still playing around with medication and stuff” (11/42).

The two other young people in this grouping reported being tested for hepatitis C because they lived with a family member who had chronic hepatitis C. Testing was also described by these young people as a precautionary measure – to ensure they were okay – but that it had not been their decision. Archie, for example, recounted how he was tested for hepatitis C twice when younger because both of his parents are hepatitis C positive. He said his grandmother would take him to be tested and recalled that one of these times was after he had “smashed” his toe with a hammer.

4.3.4.2. Occupational Requirement

Two young men described being tested for hepatitis C because of an occupational requirement. This was also the only time they had been tested and described having little or no choice. Richard recounted how he was required to be tested as part of the recruitment process for a job, while Nelson was required to be tested for a university course. He said:
R: Oh, I had to have a few blood tests for Uni, ‘cause it -- you know, clinical lessons and that sort of thing and I went to see him for that.

I: Okay, maybe you could tell me a little bit about that then, like what, what was that for like, what did you have to have done and what the reasons -- I’m not quite familiar with the medical placement stuff, but?

R: Oh, well, just went you get into med you have to be tested for Hep B, Hep C and HIV (8/15-23).

4.3.4.3. Pregnancy Related

Four young women recounted being tested for reasons relating to pregnancy. Two young women said they were tested during a pregnancy check-up, while the other two young women reported being tested as part of a termination procedure. Amy, who had two children at the time of the interview, was tested during each pregnancy. She recalled:

R: I went to the hospital for the blood tests with the girls because, when you’re pregnant you have to get those tests done.

I: Oh, okay, so it’s something that had to happen anyway?

R: Yeah.

I: Oh, okay, and um, well how’d you feel about that then, like, like those times were they?

R: Yeah, I was pretty confident, yeah, ‘cause I knew that nothing gonna - - [pause 2 secs] yeah, nothing’s gonna, you know, be happening, like nothing was there (14/33-48).

Although a pregnancy check-up and termination procedure are obviously very different experiences for young women, all these young women described the testing process in a very procedural manner. These young women did not report being presented with a choice about whether they were tested, however, they did not imply feeling coerced. Rather, it was just part of standard procedure.
4.3.4.5. Institutional Requirement

Two young people described situations in which they were required to be tested because of institutional policy or requirement, although the contexts of their stories are very different. Daryl, who had been tested for hepatitis C many times, said that he was first tested because he had been sleeping with his dad’s best friend when he was 16 years old. Daryl said that on one occasion he had been forced. His mum found out and immediately informed the police. Daryl goes on to say that the police sent him to a doctor for an examination and testing. He had no choice in the matter – he “was basically told by the cops I had to do it” (9/61).

Jodie, who was hepatitis C positive when interviewed, had also been tested several times. She recalled the first time she was tested:

The first time I was in maybe secure welfare, um, or Parkville maybe but yeah the first time I was in Parkville and I was fifteen and I knew that I’d been sharing needles with a Hep C who was -- that was my boyfriend at the time, but being fifteen, like, you know, “I’m gonna be with this guy forever, it doesn’t matter if I have Hep C”. Any fifteen year old that says that needs to be slapped over the head really hard. I’ve, I’ve had people say that to me like, last year (10/43-49).

Although she identified practices she believed would cause her to contract hepatitis C, she had not seen the need to be tested. Jodie believed she had little choice in the matter and recalled “… so they, they test you for STD’s and [other] things as well if you’ve been drug using” (12/38-39). She later said “I think they have to do it” (12/47) and that:

I was pretty naïve to it all, like you know I was -- blood’s coming out of my arm going into a bottle. Going off, I get information back on a piece of paper, you know, technically that information to me at the time, didn’t -- if it came back, you know, bad it didn’t mean crap anyway (13/19-22)
Testing was not important to her and she did not really understand the process. In fact, when reflecting on at the stage of her life, she said “back then I didn’t really care about anything” (14/20). On this occasion she tested negative and said:

*They told me I didn’t have it, so I was -- for a little while I was in, oh, my God like, aren’t I cool, I was fifteen and I’ve, I’ve been sharing needles with this guy for so long, and I haven’t even got Hep C and he does (11/26-28).*

The second time Jodie was tested for hepatitis C was when she was in Secure Welfare. She said she was talked into being tested again by a doctor. She felt she did not need to be tested because since the time she had been in Parkville she had not shared a needle – she “had that drilled into her head” (14/30-31). This time the test returned positive. Jodie also recounted her subsequent testing in a similar manner. She said that every time she changed doctors she tells them she is hepatitis C positive, to which they respond by wanting to check for themselves and she gets talked into being tested again.

**4.3.5. Further Findings**

In addition to the four major themes described above, several important ideas were reflected in the stories of the majority of young people and were not restricted to any of the themes presented above.

**4.3.5.1. Tested for “Everything”**

The majority of young people were not tested for hepatitis C in isolation but were tested as part of a battery of tests. Young people typically described this as wanting or being tested for “everything”. They also used phrases, such as being tested for “all possible things”, having “full bloods” done or “the full test”. In addition to hepatitis C, the majority recalled that they were also tested for hepatitis B and HIV but sometimes also
a range of sexually transmitted infections. Very occasionally hepatitis A was included. Ester, for example, said:

Yeah, I told them you know that, that I’ve had sex with someone and that I was really freaking out ’cause my lips had swollen up and um, you know, I wanted to get tested for everything, absolutely everything … (12/10-12).

While Scarlet, when asked about what she had been tested for in the past, revealed:

R: I’ve had the full -- I got the whole STD tests and everything done, when I had,
I: What, what sort of things did you have done when you had them?
R: Um, I had a pap test and then the blood tests for like, you know, everything, Hep and HIV, everything like that (9/37-43).

Some young people, however, could not at the time of the interview remember all of the specific tests that had been included. The most important element to being tested for these young people was having the blood tests done, finding out the results and knowing that the test was thorough and complete. Archie, when recounting what was included in the most recent series of tests, said:

… anything we could really think of, you know, I wasn’t, I wasn’t really worried on what he was searching for, I was worried on what I might have, so pretty much whatever you can check out of that, go for it, you know, I wanted -- up down, left right, I want it check -- tested all the way through you know (11/22-26).

For Dana, testing was only one part, and the least important, of a medical procedure she was undergoing. She said:
I really just wanted to get the termination over and done with because it was a real, I didn’t under, I didn’t really understand the procedure so, I wasn’t really thinking about what blood test, results and thing like that. I should have but (19/13-17).

Some young people did not seek to be tested for “everything”, although they may have been tested for a large number of infections and diseases, but were interested in knowing whether they had a specific infection(s) or disease(s). Luke, for example, recounted how he went to a doctor to specifically be tested for hepatitis B after having unprotected sex with someone who revealed she was hepatitis B positive. He remembered however, that the doctor also tested him for a number of other infections including hepatitis C and HIV. Richard and Nelson reported being required to be tested for hepatitis C and a large number of infections for occupational requirements.

4.3.5.2. Health Management, Gender, Homelessness and Hepatitis C Testing

The relationships between young people’s reasons for hepatitis C testing and health management, gender and homelessness were also examined, as they were secondary research questions for this study. The findings from these interviews reveal that hepatitis C testing was related to young people’s approach to health management, gender, and homelessness in only limited ways. Each is briefly discussed here.

4.3.5.2.1. Health Management

Young people’s style or approach to managing their health more generally was not systematically related to their approach to hepatitis C testing. For some young people it was congruent with their approach to hepatitis C testing, although this was in many different ways. Isabelle for example, whose reasons for hepatitis C testing were reflected in the theme circumstance, was typically detached from the management of her many health conditions, such as polycystic ovarian syndrome, asthma and borderline personality disorder. Although she initiated contact with doctors, she then
became a passive recipient of medical interventions. She unquestioningly leaves the
decisions and knowledge relating to the treatment of her conditions to her doctors.
Hepatitis C testing for Isabelle was simply another instance of other people, in this case
her parents and doctors, making decisions about her body and health on her behalf.

The similarity between hepatitis C testing and health management for Richard is much
different to Isabelle. Richard, like a number of other young people in this study, did not
like doctors and went to great lengths to avoid having to consult with them. When asked
about when he would go to the doctor, Richard replied:

\[
R: \text{I just wouldn’t bother [laughs]}
\]
\[
I: \text{Why’s that?}
\]
\[
R: \text{I don’t know, just [laughs] don’t like going to the doctors, never have,}
never will … it’s just something that’s always been, always tried to avoid
the doctor like I got to -- with the Army the enlistment stage, you had to
go and have a medical which is with a doctor. I managed to talk my way
out of five, six times (10/16-32).
\]

The “medical” Richard refers to also included having serological testing. As can be seen
from this extract, the medical (and hepatitis C testing) is just another medical procedure
to be avoided. He had used numerous reasons to delay the procedure, even including
needing to participate in a Project i longitudinal survey. Doctors and associated medical
procedures, such as hepatitis C testing, are something he would engage in only when he
had absolutely no other alternative. Naomi, on the other hand, held a different view to
the utilisation of health services. She had often sought help from medical practitioners,
as she has had poor health in recent times and is attempting to give-up heroin though
methadone maintenance treatment. Her use of these services is problem focused. She
said:

\[
... \text{well when I am concerned about my health, I’ll just go straight to the}
doctors and tell ’em “this is, this is what’s happening” you know, “it}
Naomi’s hepatitis C testing behaviours (see active danger, section 4.3.1.1.) before she discovered she was hepatitis C positive followed a similar matter-of-fact script. She identified a problem – injecting and sharing needles, spoons and equipment while injecting (q.v. 13/35-37) – and sought to rectify the situation through requesting testing.

This apparent similarity between hepatitis C testing and approach to health management did not follow for all young people. Lesley, as discussed within the theme safety, routinely sought testing for hepatitis C and other blood-borne viruses. She however, did not like doctors and did not seen particularly interested in what they have to say on most health issues. When asked what she normally did when concerned about her health, Lesley replied:

R: I try to avoid doctors at all costs
I: Any reasons?
R: They’re all a heap of quacks they don’t make any sense to me. It’s like why do to the doctor unless you need to. It’s like only go when you really really need to or else don’t bother (6/11-18).

To Lesley, “really really” needing to meant when all attempts to self-medicate through non-prescription medication or stimulants, such as coffee and guarana, had failed and she had becomes very sick (i.e. close to needing hospitalisation). Conversely, she sought testing for hepatitis C and B and HIV continually, approximately every three months. Although testing required Lesley to seek out a medical practitioner, it is different to other medical issues because, for her, testing was not about health but rather about feeling safe and secure.

Scarlet is a further example of the disparity between hepatitis C testing and a more general approach health management. She described regularly seeing medical doctors
for an array of issues. Her approach centred on a problems-based style of health care, as indicated in the following extract:

**I:** What, what would you do, or what do you do if you’re concerned about your health like what sort of steps do you take?

**R:** Oh, I just go straight to the doctor.

**I:** Straight away?

**R:** Yep. I’m a Medicare girl [laughs]. So yeah, bulk bill (7/42-49).

Despite this problems-based approach to health management she had only been tested for hepatitis C once in the past three years. This is despite having injected illicit drugs with her much older boyfriend for the past six to twelve months. Hepatitis C did not seem to fall into the same category of issues as other health problems. Scarlet’s position however, was not simply a knowledge related issue. Although her knowledge regarding hepatitis C was not completely accurate according to current medical evidence, for example believing it can be sexually transmitted, she expressed a strong awareness of the potential health implications of injecting illicit drugs.

### 4.3.5.2.2. Gender

The similarities and differences between young men’s and young women’s reasons for hepatitis C testing indicated an interesting, although limited, gender phenomenon. Three of the four young people in sub-theme ‘building trust’ were young men. These young people indicated they had actively sought testing for hepatitis C, and other blood-borne virus, as a way of building trust in newly formed sexual relationships. These young men took an active role in the emphasis of having testing. Testing gave these young men a way to prove they were “clean” to their girlfriends and demonstrated the commitment and openness they had for their partners.

It should also be noted that although the number of young men and young women represented in others themes indicate unequal proportions, the detail of their stories do not indicate a gendered experience.
4.3.5.2.3. Homelessness

The experience of homelessness or housing arrangements also did not appear to be systematically related to the reasons for being tested for hepatitis C. Almost all of the young people interviewed were in different living situations than when they first entered the longitudinal study. Only one young person had no housing. This young woman – Naomi – had been evicted from her accommodation on the morning of the interview and was unsure where she would spend that night. A number of young people described precarious accommodation situations; they were either contemplating moving out, in the process of moving out or were unsure of how long they would be welcome in their present accommodation. The majority of young people however, were now living with parents or guardians or in their own accommodation with a partner or friends.

A small number of the young people interviewed reported being tested for hepatitis C during an acute period of homelessness; often when living in a refuge or crisis accommodation for young people. These young people recounted engaging in practices they saw as dangerous to their health, such as unprotected sex or injecting drug use, but also implied that the environment of and people in the refuge were the source of danger. For example, Shannon, who was described within the subtheme active danger, sort testing because she had been kissing and “stuff” with young men in the refuge. In recounting her experiences she implied a belief that these practices were rendered dangerous only because the boys were “young stupid things” (12/34) of whom she was “a bit wary” (12/25).

Interestingly, two of the young women in this grouping report having injected drugs on the longitudinal surveys at about the time they were in the refuge but stated, in these interviews, that they had never injected drugs. While there is insufficient information in the interviews to adequately explore the differences in these sources of data, it is possible that the reason lies in the story they hold of their present self. These young women saw their present situation as very different to when they were living in the refuge and homeless. Shannon, for example, said:
Oh, ‘cause I was living with a few of them, they were like friends of those people and just when I was in foster care sort of thing, the, the different people that I hung around because they were in the same boat as me sort of thing, it’s like we’re all in it together sort of thing, but now that I’m on my own, I’m just -- yeah, a lot better than that [laughs] (15/51-55).

They had moved-on and now saw themselves as very different people. The characterisation of their time in the refuge as dangerous, may be a way of recasting or reconciling their histories to reflect their present situation or identity.

4.4. Summary of Results

The analysis of the interviews with young people focused on the reasons why they were tested for hepatitis C. Four major themes were identified and indicated that young people were tested for a variety of reasons. The first three themes identified – danger, safety, trust and circumstance – reflected different ways in which young people positioned themselves as active and conscious decision makers in relation to hepatitis C testing. The fourth theme – circumstance – reflected the way in which many young people did not actively seek testing or identify a need to be tested but, rather, were only tested because of a situation or context in which they found themselves. Although these themes were discussed separately, they were by no means mutually exclusive. Moreover, many young people reported different reasons for each time they had been tested for hepatitis C.

The stories of eleven young people centred on the idea of danger. These young people had sought testing for hepatitis C in response to experiencing a perceived danger. Young people experienced the danger in two ways. First, the majority positioned themselves as active participants in the danger. They choose to engage in a practice and subsequently chose to be tested. Second, a small group of young people positioned themselves as passive recipients in relation to danger. They were exposed to a danger over which they had no control but still, subsequently, chose to be tested.
The second theme to emerge – safety – was reflected in the stories of four young people. These young people initially sought testing for hepatitis C after experiencing a danger but then continued to repeatedly seek testing as a way of making themselves feel safe and secure. They felt safe in the externally verified knowledge they were infection or disease free. These young people repeatedly sought testing despite not engaging in a practice or being in a situation that they perceived as dangerous to their health. The practice of repeated testing for hepatitis C to be safe seems, in part, to stem from a belief in pervasive and unavoidable danger. These young people typically believed that no matter how hard they tried to avoid danger there was still the possibility that they could contract an infection or disease.

The theme of trust was apparent in the stories of six young people and centred on the idea that testing served a social rather than personal or medical function. This group of young people chose to be tested for hepatitis C because of issues of trust that arose between themselves and their sexual partner. For some young people, mostly young men, testing was a way to build trust in newly formed sexual relationships. It was a symbol of openness and commitment. Testing for two young women however, was due to the breaking of trust implicit in their sexual relationship. Although they undertook testing to alleviate the concern they now felt for their health because of their partner’s actions, it was primarily to alleviate the anxiety they felt about the rupture in trust implicit in their relationship. Their partner’s actions had changed their assessment of acceptable danger implicit in their relationships.

The final theme – circumstance – was apparent in the stories of ten young people. The stories of testing of these young people were quite different to those in other themes, as they positioned themselves as recipients of testing. These young people did not actively seek testing or even identify a need to be tested. They were only tested because of the context or situation in which they found themselves. There were many different situations that lead to these young people being tested for hepatitis C and included: a family member being hepatitis C positive, occupational requirement, pregnancy related, and institutional requirement.
In addition to the four themes relating to the reasons for hepatitis C testing, one other theme – tested for everything – emerged from the interviews and was an important facet to understanding why young people are testing for hepatitis C. This theme was reflected in the stories of the majority of young people and was not isolated to any of the major themes. This theme indicated that young people were not tested for hepatitis C in isolation but were, rather, tested as part of a battery of tests. Young people typically described this as wanting or being tested for everything.

The relationship between the reasons for hepatitis C testing and approach to health management, gender and homelessness were also examined. However, with the exception of gender in the sub-theme building trust, they were found to not be systematically related.

4.5. Discussion

The findings of this study suggest that young people who experience homelessness in Melbourne undergo testing for hepatitis C for many varied reasons. It should be noted that these results are not intended to present a representative view of young people’s reasons for testing. They are instead, intended to highlight the diversity of situations that can lead young people who experience homelessness to be tested for hepatitis C. Previous research on hepatitis C and HIV testing suggests that testing is often undertaken after engaging in a practice deemed risky or of concern, because of opportunity, or out of concern for other people in their life (Aitken, Kerger et al., 2002; Hughes, 2002; Loxley et al., 2000; Lupton, 1995). Although, the findings of this study share some similarity with previous research, the detail of the reasons reported here suggest a much more complex and diverse context surrounding the process of being tested for hepatitis C.

The diversity of reasons for undertaking testing for hepatitis C found in this study suggest that the assumptions implicit in associated policies (e.g. ANCAHRD, 2003) regarding testees’ motivations or reasons for testing do not always reflect the lived
experience of many young people. Far from being solely motivated by scientifically defined risk practices, young people were also motivated for psychological, social and emotional reasons unrelated to putative risk. These findings also broadly suggest that many young people assume a much more active role in the decision to be tested for hepatitis C and other infections than is often attributed to them because of the transitional stage or phase of life they occupy (Bessant, 2002; Griffin, 1997; Kelly, 2003; Mallett et al., 2006; Rosenthal, 2004; Wyn & White, 1997). This was not true, however, of all occasions young people were tested for hepatitis C. Some were tested even though they had no real desire to be tested and were tested only because of a context or situation in which they find themselves.

The apparent differences between the findings of this study and the limited number previous published may, in part, be due to differences in methodology. The two previous studies on hepatitis C testing (i.e. Aitken, Kerger et al., 2002 and Loxley et al., 2000) used limited qualitative methods, namely open-ended survey questions delivered in an interview format, while this study utilised in-depth semi-structured interviews. The methodology used in this study facilitated the collection of rich accounts of testing from young people through actively listening to their stories, as they were recounted, and probing for further clarification of their experience. This approach subsequently enabled the meaning behind their accounts to be explored in significant detail. The contrast in results may also reflect differences in the populations studied (injecting drug users vs. young people who experience homelessness). Young people who experience homelessness are not solely defined by the practices in which engage but, rather, by the broader social context they occupy. This provided a very different and largely uncaptured perspective from which to understand hepatitis C testing.

4.5.1. Danger

Not surprisingly, and consistent with the limited previous research on hepatitis C testing and the larger research on HIV testing, was the finding that many young people had sought testing for hepatitis C after experiencing a perceived danger (Aitken, Kerger et al., 2002; Loxley et al., 2000). The findings of this study, however, extend those of
previous studies by providing a detailed insight into the context surrounding such reasons for being tested for hepatitis C. Some young people actively participated in the danger (either injecting drug use or sexual practices) they experienced. Moreover, they believed they were in control of the danger and made a choice to engage in the danger. A small number however, were exposed to danger through their environment. Whether, the danger was experienced through choice or otherwise, the young people described in this theme chose to alleviate their concern by seeking testing for hepatitis C.

The dangerous practices described by young people are typically constructed as risk practices within the health and social sciences. This term was not used to describe or label these practices or reasons for testing in this study for two reasons. First the majority of young people did not frame their behaviours as risky or as a risk practice. Second, and most importantly, risk as it is often understood can implicitly blame the individual for their engagement in such practices or circumstances, as they are presumed to knowingly put themselves at risk or seek out risk. This is seen as their motivating reason for their actions and they why are morally held to account as a consequence (Lupton, 1993). This implicit assumption did not reflect young people’s accounts of these practices or situations in this study and, as such, was inadequate to label young people’s understanding of the threat of hepatitis C and other blood-borne viruses inherent in various practices or situations. This finding has direct implication for current models of testing, such as those in Australia, which are founded on the idea of a rational actor and a simple linear relationship between testing, counselling and behavioural change. This approach fails to account for the immediate contexts of their actions, which go someway to explaining engagement in such practices (Matock, 2005).

The finding that risk was not part of the vocabulary of the majority of young people interviewed was somewhat surprising, given its extensive use in everyday life and, especially, within the health and medical fields. Only one young people openly used the term in reference to their own practices, namely “sharing” needles. Another young person also used the term but only in the context of recounting the words of a health care provider during one of the occasions she was tested for hepatitis C. Instead, young people used terms and phrases, such as having a “scare”, being “paranoid” about a
practice or being simply concerned or worried. These terms and phrases reflected their psychological or emotional reaction to the danger they had experienced. These phrases suggest that young people were highly aware of some of the consequences of practices that are potentially health compromising and are actively undertaking assessments of danger. It is important to highlight that young people’s language is more than a simply rephrasing of the dominant epidemiological notion risk. Although young people readily identified the negative consequences associated with some of their practices, the context of their use was not associated with blame, as can be implied in health communication (Lupton, 1993). This finding suggests that the discourse of risk that pervades research, policy and practice is an externally imposed term on the lives of young people and does not resonate with their lived experience (Abel & Fitzgerald, 2006; Duff, 2003; Green et al., 2000; Kelly, 2005; Mitchell et al., 2001; Lawy, 2002). This is not to argue however, that young people did not recognise or were not concerned about the possible health consequences of particular practices or situations, as clearly this was the case.

This theme also demonstrates that young people are active consumers of health information pertaining to hepatitis C (and other blood-borne viruses and sexually transmitted infections). Their knowledge was however, not always in unison with scientific observations. Nevertheless, young people clearly understood that some practices and circumstances held potentially negative health consequences. This knowledge coupled with actively engaging in assessment of their own practices was generally insufficient to prevent them engaging in or avoiding danger, as is proposed and hoped by (knowledge based) prevention and intervention measures (Abel & Fitzgerald, 2006; Beardsell, 1994). This is not surprising however, given that knowledge-based health promotion measures have been shown to have little sustainable impact on behaviour change (Oakley et al., 1995; Rotheram-Borus et al., 1995; Slonim-Nevo et al. 1996). Young people were not engaging in these practices through ignorance or going out to put themselves at-risk, as is often assumed in positivist notions of risk (Lupton, 1993, 1999b). Young people actively chose to engage in danger and to disregard their knowledge at that point in time because other desires, such as to use drugs or engaged in sexual practices, were of greater importance. The role testing played for these young people was to manage or reduce the stress they experienced as a
result of these assessments and/or reconcile their choices with the potential consequences.

4.5.2. Safety

The idea of safety was central to the reasons for hepatitis C testing of four young people interviewed. These young people indicated they had initially sought testing after experiencing a danger, as described in the theme of danger, but then continued to repeatedly seek testing for hepatitis C (and other infections) because it made them feel safe and secure (Lupton, 1995). This was despite not experienced a danger (either actively or passively) since initially being tested. Interestingly, not experiencing a danger is often cited as one of the reasons that individuals decline testing or have not been previously tested (Pugatch et al., 2001; Aitken, Kerger et al., 2002; Loxley et al., 2000). However, for these young people this was clearly not the case.

These findings are similar to findings of de Rosa et al. (2001) in a study of HIV-related practices and testing among a sample of homeless young people. They found that those who reported lower perceived risk (for HIV), among other variables, were much more likely to have been tested for HIV. Moreover, the association between lower perceived risk and regular testing was found in a sample of men who have sex with men (Fernandez, Perrino, Bowen, Royal & Varge, 2003). These results suggest that engaging in repeated testing may serve to reassure an individual of their continued negative serostatus and that assessments of perceived danger may be based upon the outcome of a test rather than on engaging in specific practices (de Rosa et al., 2001; Fernandez et al., 2003). The young people in this study may have felt at lower risk – and therefore safe – because they continually had an external verification that they were infection or disease free. The need for continual reassurance of safety for these young people may also stem from a belief in pervasive and unavoidable danger or that “accidents can still happen”, even if they engaged in measures to protect one’s self. Repeated testing for hepatitis C may also reflect a more general adoption of health promoting activities in relation to hepatitis C infection (Fernandez et al., 2003), such as Daryl’s adoption of safer injecting practices.
Testing for these young people had become a routine and relatively stress free experience. This was partly because it had become a familiar experience but also because a positive result was not the expected outcome. These young people also saw that by undertaking testing they were proactively looking after their current health and protecting their future health, as also found by Lupton et al. (1995) in relation to HIV testing, and suggests that testing for these young people may be viewed as a preventive measure. Interestingly, this did not systematically extend to other health issues. This is a relatively problematic belief however, as testing only serves a preventive function at a population level and does not protect a specific individual from the possibility of infection (McCoy et al., 2003). Furthermore, the belief that testing can promote better health is also problematic, given that early detection of hepatitis C does not necessarily lead to cure, as is the case for some other infections or diseases (Lupton, 1995) and current treatment options for hepatitis C are only partially successful (AIPC, 2001; Gowans, 2001). Although treatment is now immediately available (since April 2006) to those who are newly diagnosed with hepatitis C (via a PCR test), this was not the case at the time these interviews were conducted. At that point in time only those with evidence of moderate to severe liver damage were eligible for treatment (Australian Hepatitis Council, 2006).

4.5.3. Trust

The relationship between hepatitis C (and HIV) testing and sexual relationships has been previously noted (Hughes, 2002; Loxley et al., 2000). These findings typically suggest that some people are tested for hepatitis C out of concern for other people in their life. While this also appears true for the young people described in this theme, it was not their primary motivation for testing. Rather, testing for hepatitis C served a social, rather than personal or medical, function and was related to issues of trust that emerged within their sexual relationships. Some young people, particular young men, used testing for hepatitis C as a way of building trust in newly formed sexual relationships. It was a marker or demonstration of commitment and openness with their partner, rather than an indication of mistrust. Furthermore, it provided a clean slate from
which their relationship could begin and is similar to findings by Lupton et al. (1995), who argue that HIV testing among heterosexual young people had “become a cultural icon, serving to symbolise commitment and fidelity in some relationships” (p. 179). It appears that this may also be the case for hepatitis C among some of the young people interviewed as part of this study.

The finding that young men, in particular, took an active role in emphasising testing within heterosexual relationships is interesting, as it appears to contradict earlier findings that attribute the initiation of testing to women. Young men were seen to view testing in this context as an administrative hurdle required by their partners, primarily for the purposes of discontinuing condom use (Lupton et al., 1995). Although it is difficult to determine why these results differ, it may be that in the intervening decade between these studies there has been a shift in the value and use young men place on knowledge about their bodies and blood-borne viruses in the context of sexual relationships.

The relationship between hepatitis C testing and sexual relationships may be as a result of conflating hepatitis C with sexually transmitted infections, such as HIV. More specifically, these young people may have believed it was important to be tested for hepatitis C because they believed it was sexual transmitted. Hepatitis C knowledge among young people in Australia is typically poor, particularly in regard to the role of sexual practices in transmission of the virus (Lindsay et al., 1999; Myers et al., 2005; Smith et al., 2003). This was evident among the young people interviewed in this study. Alternatively, these young people may have simply assumed it was included in the typically large number of tests they had performed, when, in fact, it may not have been. However, given that these young people often specifically recalled being tested for hepatitis C, this explanation is unlikely. Furthermore, many of these young people had histories of engaging in injecting drug use, which may have emerged during the course of the health consultation and led to hepatitis C testing.

The idea that testing can provide a clean slate from which a newly formed sexual relationship can proceed ignores the reality that their partner may subsequently engage
in practices that have the potential to introduce infections from an external source to the relationship (Lupton et al., 1995). This is precisely what occurred for two young women and is captured by the second sub-theme ‘breaking trust’. This sub-theme has not been explicitly reported in previous research. Lupton and colleagues (1995), in their research on HIV testing, reported that some interviewees sought testing at the end of a relationship but suggest, rather, that it was associated with ideas of purity and responsibility. The scenarios described by the young women in this study were not necessarily the end of the relationship (although may have been) and were primarily associated with the breaking of trust implicit in their relationship. It is possible that this sub-theme has been reported by participants in previous research but was categorised as seeking testing after a perceived danger (or risk). The detail contained in the stories of these young women however, indicates that their reasons for testing were more than an account of perceived danger. Instead, testing was primarily to alleviate the anxiety they felt concerning the rupture in the trust implicit in their relationship directly caused by the actions of their partner.

4.5.4. Circumstance

A finding consistent with previous hepatitis C (and HIV testing) research was that some young people were tested for hepatitis C because of the situation or circumstance in which they found themselves. Many of the reasons for testing described by the young people in this study however, have not been captured in previous research. Consistent with the prevalence and incidence analyses, discussed in the previous chapter, was the finding that some young women were tested during pregnancy, either as part of antenatal care or a termination procedure. An unexpected reason for testing was offered by two young men who indicated they had been tested because of educational and occupational requirements and three young people were tested because a family member was hepatitis C positive. Notably absent from the findings of this study was that some people report being tested for hepatitis C because of participation in a research project or financial incentive (Aitken, Kerger et al., 2002; Riess et al., 2001). Furthermore, only one young woman reported being tested at the recommendation of a doctor or health practitioner while in juvenile justice detention. Testing as part of a drug
treatment program was not reported. Loxley et al. (2000), by comparison, found that approximately one-quarter of injecting drug users had been tested in either of these settings.

The significance of this theme is that many young people who experience homelessness undergo hepatitis C testing as a result of indirect coercion or lack of choice. Although these young people report agreeing, or at least had not strongly objected, to being tested for hepatitis C, they were also typically placed in a situation where they felt they had little choice but to accept because the request or suggestion had come from someone in a position of power (e.g. a parent, doctor or police officer). In some cases the very offer of testing generated fear and anxiety. These young people typically did not identity a need to be tested and had a very low (or non-existent) expectation of a positive result (i.e. that they had an infection). These young people typically did not have a history of injecting drug use and would, according to epidemiological information about hepatitis C, have a very low probability of being infected. It is however, still possible that they had engaged in other practices (not captured during the course of the interview) that may have led to a highly unexpected test result.

Interestingly, these young people typically describe the procedures of the health care practitioner surrounding the testing episode as not complying with those outlined in testing policies (e.g. ANCAHRD, 2003; DHS, 2002; RACGP, 2003), which may have left them unprepared to receive a diagnosis. Furthermore, even if the current recommended testing procedures had been followed, they may have been insufficient or inappropriate in these situations, as current testing policies are not founded on coercive (implied or otherwise) testing environments.

### 4.5.5. Tested for Everything

Reflected in the stories of the majority of young people and evident in all of the themes discussed was the finding that hepatitis C testing was typically not undertaken in isolation. Many young people described this as wanting or being tested for everything. This finding supports the prevalence and incidence analyses and is, generally, consistent
with research conducted with injecting drug users by Loxley and colleagues (2000). The findings of this study however, suggest a more complex relationship between testing for different infections. Some young people described seeking testing for a range of specific infections, which also included hepatitis C, while others wanted testing for a specific infection but ended up being tested for a large number of infections due to the recommendations or decisions of their health care provider. For a number of other young people however, the specific detail of the types of tests they received was much less important than the result of the tests (Lupton et al., 1995). These young people wanted and needed to know they were okay and free of all infections.

The high cross-testing rates between hepatitis C and sexually transmitted infections, especially among those who sought testing for a range of specific infections including hepatitis C, may be as a result of overestimating the importance of the sexual transmission of hepatitis C. This is reflected, in part, within the theme ‘trust’ and the stories of young people who sought testing after experiencing danger relating to sexual practices. However, such an hypothesis is difficult to adequately assess given that some of these young people had also injected illicit drugs on one or more occasions.

4.5.6. Limitations

The principal limitation of this study is the relatively small number of interviews conducted, especially with hepatitis C positive young people. It is possible that the findings presented here may not represent the motivations or reasons for testing of other young people who experience homelessness or generalise to other populations. It was however, not the aim of this study to make statements of representativeness, but to document and examine the detail contained in the stories of the young people in this study. Given the diversity of reasons captured in these interviews, it seems that this aim has been achieved.

A second limitation of this study is that the analysis relies solely on the accounts of the young people. This may present a biased account of testing, as young people may present an overly positive picture of themselves, while ignoring potentially negative
detail. An example of this may be in the apparent discordance between the longitudinal survey responses and qualitative interviews of two young women in relation to injecting drug use. The aim of this study was to understand testing for hepatitis C from young people’s experience, however it is presented. Furthermore, young people typically appeared open and honest in their responses to questions during the interviews and spontaneously recounted highly personal and sensitive experiences, such as those relations to drug use and sexual relationships.
Chapter 5
Looking Forward: Issues and Ideas for Hepatitis C Testing

The aim of this thesis was twofold. First, to examine patterns of hepatitis C testing among young people who experience homelessness in Melbourne and how they relate to behavioural and contextual factors, and second, to examine the social, behavioural, psychological and environmental contexts in which hepatitis C testing occurs for young people who experience homelessness. To address the first and second aims, respectively, longitudinal panel surveys and semi-structured qualitative interviews were completed with young people in Melbourne who had recently become homeless for the first time.

The combined findings of these studies indicate that hepatitis C testing was a very common experience among young people who experience homelessness in Melbourne and that the characteristics of those tested and the reasons for testing were considerably different to those endorsed or implied by current testing policies in Australia. In understanding the myriad of approaches to hepatitis C testing evident among young people who experience homelessness several key ideas emerged: a reinterpretation of risk, active help seeking, pregnancy, and testing for other blood-borne or sexually transmitted infections. These points are discussed in greater detail below.

5.1. Risk: More than Simply Blame

The idea of risk, as it is typically understood within the health and social sciences, fails to adequately capture the breadth of the very common experience of hepatitis C testing among young people who experience homelessness. This research found that standardised measures of blood-borne virus risk, such as sharing needles, syringes and injecting equipment, being tattooed or pierced by a non-professional and sharing other’s hygiene products and utensils, and most other ways of measuring risk practices, such as injecting drug use, use of specific drugs and sexual practices, have little association with recent or first time hepatitis C testing. Furthermore, many of the reasons young people
gave for engaging in hepatitis C testing did not relate to the idea of risk and indicated that testing served many other important functions. The problem with the current literature and application of the risk and at-risk discourse is that it presents a single view of the “reality” of young people and ignores or excludes other factors that influence these accounts (Rosenthal, 2004), which in this study were clearly important.

This it is not argued that those who inject illicit drugs or engage in other practices deemed likely to transmit hepatitis C were not tested for hepatitis C or that these practices were not important reasons for testing for some young people. There was some evidence that engaging in such practices did relate to testing for some young people in this research. The analysis of recent and first time hepatitis C testing, for example, offered some evidence for a relationship between injecting drug use and testing for hepatitis C, however when other measures were taken into account, injecting drug use was found to contribute little to explaining testing in either model. There was also some evidence, although not particularly strong, of a relationship between some measures of drug use, sex-related alternative sources of income and hepatitis C testing. Accessing a NSP was the strongest predictor of recent testing. Exchanging needles at a NSP strongly suggests that these young people also engage in injecting drug use and, as such, can serve as an indirect measure of potential exposure to blood-borne viruses. However, accessing a NSP also suggests that young people are potentially injecting in particular ways, such as with new needles and syringes, and may have actively adopted public health messages relating to injecting in safer ways, which may also include testing. Moreover, many young people suggested that engaging in scientifically identified risk practices was the reason why they were tested. Notwithstanding this contribution to understanding hepatitis C testing, this research found that within the context of other factors examined so-called risk practices were less important. The relative unimportance of epidemiological risk may also reflect that many of those who had engaged in practices likely to transmit hepatitis C had not been tested and that there were many and diverse reasons for testing unrelated to potential exposure to hepatitis C.

The findings from this research also suggests that the discourse of risk that pervades the hepatitis C research, policy and practice is an externally imposed term on the lives of
young people and does not resonate with their lived experience. Young people did not use the term when describing the self-defined dangerous practices that lead some to seek testing for hepatitis C. They instead used terms and phrases, such as having a “scare”, being “paranoid” about a practice or being simply being concerned or worried, that reflected their psychological or emotional reaction to the danger they had experienced. It is important to note that the language used by young people in this research to express their reaction to engaging in danger was more than a simple rephrasing of the idea of epidemiological risk. A commonly implied element of health promotion and illness prevention discourse is blame. Those who engage in risky or dangerous practices are presumed to knowingly put themselves in these situations. This is seen to be their motivating reason for their actions and, accordingly, why they are morally held to account for their behaviour (Lupton, 1993). Young people’s retelling of danger did not however, contain moral elements. Although it can perhaps be expected that young people, or indeed any other individual, would not consciously condemn their own actions or situation, these findings suggest that prevention and intervention programs that implicitly convey this idea may have minimal effect on changing behaviours, as it does not resonate with young people’s lived experience and interpretation of their own practices.

The terms used by young people to describe dangerous practices also demonstrate their implicit understanding of the potential negative outcomes associated with such practices and that they were actively undertaking assessments of their own actions. These assessments were, however, different to what is assumed or hoped by health practitioners (Abel & Fitzgerald, 2006).

5.2. Active Help Seeking

An important factor in understanding hepatitis C testing, in the context of this study, was actively seeking help from the social and health service sector. Obviously, to be tested for hepatitis C or another blood-borne virus requires contact with a health service, however, these findings suggest that acting on a perceived need is more important to being tested than simply engaging in a particular practice or displaying a particular
characteristic, such as illness, gender or age. Young people who experience homelessness are actively seeking out help for health issues relating to blood-borne virus infection by accessing appropriate services, whether it was motivated by a specific danger or for social or emotional reasons. Active help seeking behaviours have been observed in other recent studies of young people who experience homelessness in relation to a number of health and social issues (Barkin et al., 2003; de Rosa et al., 1999; Rew et al., 2002; Rossiter et al., 2003). This capacity however, is typically not attributed to them within the typical conceptualisation of young people (Bessant, 2002; Griffin, 1997; Kelly, 2003; Mallett et al., 2006; Rosenthal, 2004; Wyn & White, 1997). Interestingly, young people’s approach to testing did not appear to systematically extend to other health issues. These findings also indicate that some young people are conscious consumers of health information pertaining to hepatitis C, other blood-borne viruses and sexually transmitted infections. This knowledge is not always in unison with medically accepted observations but, nevertheless, further indicates that young people understand the potentially negative consequences to their health inherent in some practices and circumstances.

The finding that young people who experience homelessness are actively seeking hepatitis C testing from health and social services demonstrates the value in employing multi or mixed methods designs – that is, using qualitative and quantitative techniques in tandem – to investigate health issues. Far from being diametrically opposed in both aim and outcome, as is often seen to be the case (Creswell, 2003; Hedrick, 1994; House, 1994), the use of quantitative and qualitative methods has provided different ways to understand or view hepatitis C testing in this research. Analysis of the longitudinal survey data, for example, indicated the magnitude of the relationship between service use and hepatitis C testing was very strong, however, it was only able to propose the active role young people played in driving this association as one of several possible interpretations. Analysis of the semi-structured interview data enabled the interpretation of the more distant group statistics through providing rich individual-level detail that categorically highlighted that hepatitis C testing for many young people was a deliberate and conscious action. This is not to simply say that the qualitative findings were in any way subordinate to the quantitative findings and merely provided an interpretive tool for
the longitudinal survey data. Rather these methods have provided different windows through which to view the phenomenon of hepatitis C testing among young people who experience homelessness in Melbourne (Chamberlain et al., 1997; Denzin & Lincoln, 2000; Hathaway, 1995).

5.3. Pregnancy

The significant role of pregnancy in the practice of hepatitis C testing was apparent in both the longitudinal and thematic analyses. It draws attention to the fact that many young women are routinely tested for hepatitis C as part of antenatal care or termination procedures. Whilst this may not seem an unexpected finding, given that separate billing codes are allocated to screening during pregnancy in the Medicare Benefits Schedule Book (DHA, 2005), the extent to which it occurs and the perception of the lack of true choice in these testing situations was surprising. These young women typically believed that hepatitis C testing was part of the “standard procedure” of an antenatal check-up or termination procedure. The national guidelines for hepatitis C testing stipulate that pregnant women should only be tested in the presence of a scientifically identified risk practice (ANCAHRD, 2003). This research clearly indicates, however, that the approach may be more generalised, as many of the young women in this study tested in these situations did not have a history of injecting drug use and/or did not report medical practitioners undertaking a risk assessment.

This testing pathway has not been documented in previous research, although a small number of studies have examined the relationship between scientifically identified risk factors for hepatitis C and infection among pregnant women (e.g. Garner et al., 1997). There is a clear need for research on the impact of hepatitis C testing in relatively benign situations, such as antenatal care, on people’s experiences and outcomes of testing. An approach to hepatitis C testing – presented as the standard practice or “policy” of a service – may make women feel comfortable about being tested in such an emotionally charged setting but it ill-prepares them for the possibility of a positive test result and the ability to make an informed choice.
5.4. Testing for Other Blood-borne or Sexual Transmitted Infections

The findings of this research indicate a very strong relationship between hepatitis C, HIV and STI testing. Results from the longitudinal surveys indicated that the majority (79%) of young people who had been tested for hepatitis C had also been tested for HIV and one or more STI in the same three-month period. The link between hepatitis C testing and HIV testing is not surprising, given the role injecting drug use has in the transmission of these viruses (Crofts et al., 1999) and the similarity in the way testing is performed (i.e. through intravenous blood collection).

It is possible that young people thought of these tests as a single test and responded in the affirmative when asked about each infection, as has been suggested in previous research (Loxley et al., 2000). The results of this research, however, suggest a much more complex relationship than has been previously described. A number of young people described being tested for a range of infections (of which hepatitis C was presumed to be part) however the nature of the specific tests performed was much less important than the results of the tests. These young people simply wanted to know they were free of any infection. Many other young people in the research were specific in their assertion that they had been tested for hepatitis C. These included young people who, through their own assessments, had clear ideas of the range of specific infections they wanted to be tested for, and others who had sought testing for a single specific infection but had ended up being tested for a large number of infections, due to the recommendations or decisions of the consulting health care provider. The experience of the latter group of young people is consistent with the practice of testing, as described by health care providers (during informal discussions held over the course of this thesis) employed at services and agencies that provide blood-borne virus testing in Melbourne. These workers indicated they routinely assess scientifically identified risk practices among their clients and offer appropriate testing.

The relationship between testing for hepatitis C and other STIs is not as straightforward to explain as HIV testing, given the clearer differences in the modes of transmission between these infections and hepatitis C. This association may, in part, be due to the
dominant stereotype held by service providers that young people who experience homelessness are an at-risk group who engage in many practices, such as injecting drug use and unprotected sex, that increase the likelihood of contracting hepatitis C and other infections (Mallett et al., 2001; Myers et al., 2002). Such a belief may lead to a generalised medical response to young people who are assumed to be homeless or transient. Presented with a young person they believe to be at risk because they are homeless (or are in the least accessing services designed from such young people) and who may not access the service again, many service providers may pursue testing because it is a good or only opportunity they have to test them.

5.7. Limitations of this Research

There are a number of limitations of this research that warrant discussion here. The first issue relates to the potential influence participation in a longitudinal research project has on the behaviours and circumstances of those studied. In particular, involvement in this study required young people to reflect on and articulate their present situation and behaviours. This may have led to an increased interested in their health and well-being and, as a consequence, produced the high rates of hepatitis C testing observed. Rates of testing did increase significantly over the course of this study, however it should be noted that hepatitis C testing was a very common practice among these young people even at baseline. Although this issue should be considered when interpreting the findings of this research, it is by no means a concern limited to longitudinal research and is, in fact, a feature of any research methodology.

Second, the sample sizes employed in both the quantitative and the qualitative studies were relatively small. The sample sizes employed were still sufficient to conduct meaningful statistically analyses (although not to adequately explore some statistical interactions) and reach thematic saturation. Moreover, it was well beyond the scope and resources of this research to have recruited and tracked greater numbers of young people who experience homelessness.
Third, this thesis aimed to extend the understanding of hepatitis C testing beyond an epidemiological risk framework by employing an array of social, behavioural and contextual factors. A large number of variables were examined however, it was limited to those available at multiple survey waves (as discussed in 3.2.2. some measures were not available at all survey waves). There are still a number of avenues that may be important to understanding the context of hepatitis C testing including the influence of social networks and social supports on testing.

A fourth and final limitation is the extent to which the findings of this research can generalise to the broader population of young people who experience homelessness. Questions about representativeness are a constant problem for research with this population. Young people who experience homelessness are a difficult population to define and there is currently no single agreed upon definition (Chamberlain & MacKenzie, 1998; Fopp, 1992, 1993; Mallett et al., 2006; Robertson, 1992). They are often highly mobile in their living arrangements, are indistinguishable from home-based young people and do not necessarily identify themselves as homeless (Chamberlain & MacKenzie, 1998; Ringwalt, Greene, Robertson & McPheeters, 1998; Robertson, 1992). These considerations make it exceedingly difficult, if not impossible, to identify these young people let alone employ a random sample. This research however, did not seek to make claims of representativeness or generalisability. Instead, this research attempted to recruit a diverse cohort in order to reflect the experiences of as many different young people who had become homeless for the first time as possible. The decision to sample according to principles of diversity, rather than representativeness, was also based on the criticism that previous research on young people who experience homelessness had almost exclusively focused on a small segment of the population, namely, those “living rough” on the street or in crisis accommodation and who have been homeless for longer periods of time. In this sample, less than 10% had lived on the street at any stage during the research. A larger proportion had stayed in short-term, crisis or emergency accommodation however, the majority had resided with an extended family member, with friends or a partner, in transitional (medium-term) housing or, after baseline, found a own place of their own. The sample of young people recruited
for this research, as such, reflects the wide diversity of young people who experience homelessness, rather than being statistically representative of the population.

5.8. Future Directions for Research

Given the dearth of research on hepatitis C testing in Australia and internationally, significantly more research needs to be conducted to adequately understand the practice of testing. The research presented here has demonstrated that far from being a resolved or redundant issue, since the establishment of broadly accepted testing policies, there is still much to be learned about who and why people tested for hepatitis C. These questions are particularly important because it appears that the practice of testing, as observed in the young people studied here, is not in unison with the intention of policy designed to regulate the practice. This has significant implications for health care and social service budgets.

Research on hepatitis C testing would greatly benefit from extending examination to other segments of young people and the broader population. This would yield valuable information on the reasons why such large numbers of tests are conducted each year, particularly among those who have never injected illicit drugs. This research would widen current knowledge to a population statistically more likely to engage in scientifically defined risk practices but one that is not solely defined by these practices, as has been the case in the majority of previous hepatitis C testing research. It is possible that the closer to the general population a research sample resembles the less relevant epidemiological risk factors are in determining who and why people are tested. Comparisons between different countries would also provide a useful avenue of inquiry. Although the findings from cross-national research may prove difficult to interpret due to differences in social, political and economic structures, it would potentially provide insight into the more effective aspects of testing strategies.

There is a clear need for research into the impact choice or, more precisely, the lack of choice has on the process and experience of hepatitis C testing. Current testing policies require informed consent to be obtained before testing can proceed however, this
research has shown that many young people were tested in situations where little or no choice was apparent. This may leave testee’s unprepared to manage the stress associated with serological testing and/or the possibility of facing a diagnosis of a stigmatising infection that will significantly affect their health and well-being for many decades.

The current small body of literature on hepatitis C testing has focused exclusively on the perspective of those who receive testing. Another perspective that warrants examination is those who perform testing. This would provide insight into how testing policies are translated in practice by frontline health care workers and the barriers or issues they may face when delivering prescribed practices. Greater understanding of the relationship between practice and policy from the tester’s perspective would also help interpret users experience of testing by providing insight into another aspect of the context in which testing occurs.

5.6. Implications for Hepatitis C Testing Policies

Current hepatitis C testing policies in Australia and many other developed countries assume that those who undergo testing have made a choice to be tested, undergo testing solely for medical or health-related reasons, and/or have a desire to change the practices that have caused them to need testing. While this was true for some young people in this study, many others were tested for hepatitis C in situations or circumstances unaccounted or unacknowledged within these policies. These findings suggest that a more nuanced approach to testing is required in order to promote more positive experiences and outcomes for the recipients of testing (Loxley et al., 2000) and broader public health concerns, such as the prevention of hepatitis C transmission in the community and the cost to the health care system. The specific form this may take, however, is beyond the scope of this thesis to state conclusively.

The findings of this research point to the need to educate medical practitioners on the intricacies of the context in relation to hepatitis C testing. In particular, this research points to the importance of carefully and critically examining the reasons why young people ask to be tested for hepatitis C, in order to establish whether testing is serving a
non-medical function. In this event it is warranted to suggest more appropriate courses of action to address their concerns when necessary. These findings also suggest that an open dialogue must also be established between the tester and the testee in order to facilitate discussion about so-called risky practices; one that does not convey blame to young people for the practices they choose (or otherwise) to engage in. If this does not occur it is unlikely young people would reveal these practices and the presumed preventive role testing can play would be countered. While frontline health care workers at services for injecting drug users across Melbourne report (during informal discussions held throughout this research) approaching testing in this way, many of the young people involved in this research were not tested in such environments – often by a general practitioner in a private clinic. Many also recounted very different and often far from ideal experiences of hepatitis C testing.

Attempts to vigorously target specific individuals for hepatitis C testing – that is, those deemed at high risk according to epidemiological evidence – may have produced a climate where low risk individuals feel they need, and consequently seek, testing. A similar trend has been observed in patterns of HIV testing uptake in Australian and Europe (Lupton et al., 1995; Zwahlen et al., 2000). From a utilitarian public health perspective this may seem a worthwhile endeavour, if testing is assumed to fulfil a preventive role when coupled with pre- and post-test counselling and discussion. However, testing large numbers of people is expensive. Given the ever decreasing relative budgets of departments and agencies responsible for health care in Australia and the projected increases in health care expenditure due to other pressures, such as an aging population and increasing cost of pharmaceuticals, a situation could arise whereby the capacity of the health system fails to adequately meet the needs of those designated as most in need. Consequently, the effectiveness of hepatitis C testing, as a preventive measure, is lost.

The numerous episodes of hepatitis C testing described by young people in this study that occurred with little or no perceived choice is of concern, particularly because they were not approached as outlined by testing policies. Diagnostic testing, no matter the medical condition, can be a very stressful event as the testee must confront the prospect
of having an infection and weigh up the benefits to themselves of actually knowing such information (Ickovics et al., 1998; Worthington & Myers, 2003). Pre- and post-test counselling and discussion is, in part, intended to allay these concerns. While the probability of the young people tested in these circumstances returning a positive test result varied considerably, none would have been adequately prepared to receive a positive result if this had, in fact, actually occurred. Moreover, even if the recommended hepatitis C testing procedures had been followed, it would have been insufficient or inappropriate, given that current policies are not founded on coercive (implied or otherwise) testing environments. Testing should not be performed on the basis that a particular situation simply presents a good opportunity to screen members of the general population or particular groups within the population, for example those in state custody or those receiving antenatal care. However, if large scale screening for hepatitis C is to continue, then approaches to testing must be developed that will adequately prepare testees. In particular, this approach would need to focus on how to successfully communicate and provide real choices as to whether testing is performed or not.

Some young people who experience homelessness engage in practices that place them at increased likelihood of contracting hepatitis C. An implication of the results of this research is that the state of homelessness among young people should not be seen, in and of itself, as a reason for offering hepatitis C testing. This is particularly true given the time it can take for serology to be processed and reported and the highly unstable housing situation of these young people. These considerations mean it is quite likely the young person would not return for their test result. This not only wastes the time and resources of health services but also unnecessarily increases testees’ anxiety. Given that many young people do appear to be actively seeking help for health issues relating to blood-borne and sexually transmitted infections, such a generalised response is unfounded. This is not to suggest that services should not offer hepatitis C testing to young people who experience homelessness but, rather, that they should not be offered testing simply because they are homeless.

This research has highlighted that, far from being a resolved or redundant issue, there is still a great deal more to be learnt about the human factors associated with hepatitis C.
testing. The numerous ways in which young people who experience homelessness have engaged in hepatitis C testing in this research show that the current assumptions and approaches to testing must be rethought. Public health researchers and practitioners need to closely look at what is hoped to be achieved through testing policy and practice and how such aims can best be achieved.
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Appendix A

Plain language statements and informed consent forms for longitudinal surveys with recently homeless young people.

Separate forms were provided for:

- young people aged 12-17 years
- young people aged 18 years and older
- parents of young people aged 12-17
Confidentiality - we'll be just as careful as you...

We're interested in you, and we're careful not to put your name on any of the information you provide. The researchers will give you a pseudonym or false name and store any information that you provide under that name. Once we have transcribed any audiotape recordings made during an interview we will erase the tape. Any names used during an interview will be replaced by pseudonyms or false names. Any information that might identify you or your family and friends will be changed. Only the researchers immediately involved in this study will have access to the original information you provide. Everything you tell us will be held confidentially subject to legal requirements. Normally, the researchers cannot guarantee absolute confidentiality with respect to illegal behaviour of which they are made aware. If you reveal current physical or sexual abuse, and/or suicidal/homicidal feelings, a report must be made and action taken to protect you and others.

All information will be stored on computer files at a central location and these files will be protected by a password known only to the researchers involved in the project. These researchers are the only people who will have access to these files. The tapes and the computer will be kept under lock and key.

What will happen to the findings from this research...?

The findings from the study will be written on the website, in community reports, pamphlets, and books and in academic journals.

If you have any questions...

If you have any questions about the research you are very welcome to phone Shelley Mallett (Research Fellow, PhD) at The University of Melbourne on 8344 0245. You can also email her on smallett@unimelb.edu.au.

The Ethics Committee at The University of Melbourne has given approval for this study. If you have any concerns about the way you were treated during the study or queries that the researcher was not able to answer to your satisfaction please contact the Human Ethics Committee as follows:

Ms Kate Murphy
Executive Officer
Human Research Committee
Walter Boas Building,
The University of Melbourne
Tel: (03) 8344 7507
Email: k.murphy@unimelb.edu.au
Some info about project i ....

We are a group of researchers at The University of Melbourne who are interested in why young people become homeless and what they do once they are no longer living at home. We want to learn about what young people do to get by once they leave home: who they hang out with; who gives them support and care; what services they use; and what they think about these services. We also want to understand how young people manage their health.

We invite you to be part of a three year study, which will involve (up to four) interviews each year. You will be reimbursed between $20 and $40 for doing each interview. The longer you stay with the project, the more you will be reimbursed for an interview.

If you agree to be part of the study you will be put in touch with an interviewer who will tell you what is happening with the project.

Why did you ask me to participate? because you are:

between the ages of 12 and 17,
- you were asked or ordered to leave home, or left without your parents/guardians consent less than six months ago,
- you may be receiving services from one of the agencies participating in the research.

What's involved?

You will be asked to do (up to three) interviews each year that will take between 1 and 1 1/2 hours each time. During each interview you will be asked to complete a survey that asks questions about your background, the places you have lived, the people who support you, your drug use, sex life and your education.

Who will benefit from the project i research?

Studies such as this give you an opportunity to tell us what you think about the issues that affect you. From this we will:
- learn about the issues for young people who are not living at home,
- learn about the different paths young people follow when they leave the family home,
- have greater understanding of the ways in which young people learn to look after themselves when they are not living with their families,
- learn how to assist health professionals, social workers and youth workers to help young people reduce their risk of contracting HIV and HEP C,
- learn how governments, services and health professionals can improve services for homeless young people.

Voluntary Participation

Your participation in this project is completely voluntary and will not affect your ability to receive services at any agency or organisation affiliated with the project. If you do participate in the study you can refuse to answer any of the specific questions in the interviews.

Are there any risks for me in being involved in the project?

This project will not bring any physical risks to you. However, talking about your family background and your personal, sexual and drug using experiences may make you feel uneasy.

Keeping in contact...

We would like to stay in touch and interview you up to three times a year for three years. To do this we will need to contact you from time to time. The researcher will ask you for contact information. This might include things like your current address, phone number, hotmail (if you have one), and the contact details of a third person(s) who could put us in touch with you. We might also ask if we could contact you through a service or agency that you have contact with.

Any information about your whereabouts or information about you that is given by services or workers will be kept strictly confidential by the research team staff. We will not contact your parents; but if you would like us to contact them, we would be happy to.
Project i - Statement of Informed Consent

**Research:** Project i  
The University of Melbourne

**Researcher:** Dr Shelley Mallett (Research Fellow).

- I agree that I have read and understood the information about this study provided on the pamphlet called ‘Information for Recently Homeless Young People (Aged 12-17) Participating in Project i’.

- I agree that I have been given a copy of this sheet and any questions I have asked have been answered to my satisfaction.

- I agree to take part in this study, knowing that that I may withdraw at any time.

- I agree that research data collected for this study may be published or provided to other researchers on the condition that no names or other identifying characteristics will be used. I have been informed that the confidentiality of the information I provide will be safeguarded, subject to legal requirements.

Participant

Name_______________________________________
*(First name or pseudonym)*

Signature____________________________________

Date________________

Researcher

Name_______________________________________

Signature____________________________________

Date________________
*(month/day/year)*
Confidentiality - we’ll be just as careful as you...

We’re interested in you, and we’re careful not to put your name on any of the information you provide. The researchers will give you a pseudonym or false name and store any information that you provide under that name. Once we have transcribed any audiotape recordings made during an interview we will erase the tape. Any names used during an interview will be replaced by pseudonyms or false names. Any information that might identify you or your family and friends will be changed. Only the researchers immediately involved in this study will have access to the original information you provide. Everything you tell us will be held confidentially subject to legal requirements. Normally, the researchers cannot guarantee absolute confidentiality with respect to illegal behaviour of which they are made aware. If you reveal suicidal and/or homicidal feelings, a report must be made and action taken to protect you and others.

All information will be stored on computer files at a central location and these files will be protected by a password known only to the researchers involved in the project. These researchers are the only people who will have access to these files. The tapes and the computer will be kept under lock and key.

What will happen to the findings from this research…?

The findings from the study will be written on the website, in community reports, pamphlets, and books and in academic journals.

If you have any questions…

If you have any questions about the research you are very welcome to phone Shelley Mallett (Research Fellow, PhD) at The University of Melbourne on 8344 0245 or 1800 676 100. You can also email her on smallett@unimelb.edu.au.

The Ethics Committee at The University of Melbourne has given approval for this study. If you have any concerns about the way you were treated during the study or queries that the researcher was not able to answer to your satisfaction please contact the Human Ethics Committee as follows:

Ms Kate Murphy
Executive Officer
Human Research Committee
The University of Melbourne
Tel: (03) 8344 7507
Email: k.murphy@unimelb.edu.au
Some info about project i ....

We are a group of researchers at The University of Melbourne who are interested in why young people become homeless and what they do once they are no longer living at home. We want to learn about what young people do to get by once they leave home: who they hang out with; who gives them support and care; what services they use; and what they think about these services. We also want to understand how young people manage their health.

We invite you to be part of a three year study, which will involve (up to three) interviews each year. You will be reimbursed between $20 and $40 for doing each interview. The longer you stay with the project, the more you will be reimbursed for an interview.

If you agree to be part of the study you will be put in touch with an interviewer who will tell you what is happening with the project.

Why did you ask me to participate?

because you are:

- between the ages of 18 and 20,
- you were asked or ordered to leave home, or left without your parents/guardians consent less than six months ago,
- you may be receiving services from one of the agencies participating in the research.

What’s involved?

You will be asked to do (up to three) interviews each year that will take between 1 and 1 1/2 hours each time. During each interview you will be asked to complete a survey that asks questions about your background, the places you have lived, the people who support you, your drug use, sex life and your education.

Who will benefit from the project i research?

Studies such as this give you an opportunity to tell us what you think about the issues that affect you. From this we will:

- learn about the issues for young people who are not living at home,
- learn about the different paths young people follow when they leave the family home,
- have greater understanding of the ways in which young people learn to look after themselves when they are not living with their families,
- learn how to assist health professionals, social workers and youth workers to help young people reduce their risk of contracting HIV and HEP C,
- learn how governments, services and health professionals can improve services for homeless young people.

Voluntary Participation

Your participation in this project is completely voluntary and will not affect your ability to receive services at any agency or organisation affiliated with the project. If you do participate in the study you can refuse to answer any of the specific questions in the interviews.

Are there any risks for me in being involved in the project?

This project will not bring any physical risks to you. However, talking about your family background and your personal, sexual and drug using experiences may make you feel uneasy.

Keeping in contact…

We would like to stay in touch and interview you up to three times a year for three years. To do this we will need to contact you from time to time. The researcher will ask you for contact information. This might include things like your current address, phone number, hotmail (if you have one), and the contact details of a third person(s) who could put us in touch with you. We might also ask if we could contact you through a service or agency that you have contact with.

Any information about your whereabouts or information about you that is given by services or workers will be kept strictly confidential by the research team staff.

We will not contact your parents; but if you would like us to contact them, we would be happy to.
Project i - Statement of Informed Consent

Research: Project i
The University of Melbourne

Researcher: Dr Shelley Mallett (Research Fellow).

- I agree that I have read and understood the information about this study provided on the pamphlet called ‘Information for Recently Homeless Young People (Aged 18-20) Participating in Project i’.

- I agree that I have been given a copy of this sheet and any questions I have asked have been answered to my satisfaction.

- I agree to take part in this study, knowing that that I may withdraw at any time.

- I agree that research data collected for this study may be published or provided to other researchers on the condition that no names or other identifying characteristics will be used. I have been informed that the confidentiality of the information I provide will be safeguarded, subject to legal requirements.

Participant

Name_______________________________________
(First name or pseudonym)

Signature____________________________________

Date_________________

Researcher

Name_______________________________________

Signature____________________________________

Date__________________
(month/day/year)


Confidentiality - we'll be just as careful as you...

We're interested in your child, and we're careful not to put his/her name on any of the information s/he provides. The researchers will give your child a pseudonym or false name and store any information that s/he provides under that name. Once we have transcribed any audiotape recordings made during an interview we will erase the tape. Any names used during an interview will be replaced by pseudonyms or false names and any information that might identify your child or your family and friends will be changed. Only the researchers immediately involved in this study will have access to the original information your child provides. Everything they tell us will be held confidentially, subject to legal requirements. Normally, the researchers cannot guarantee absolute confidentiality with respect to illegal behaviour of which they are made aware. If your child reveals suicidal and/or homicidal feelings and intent, a report must be made and actions taken to protect him/her and others.

All information will be stored on computer files at a central location and these files will be protected by a password known only to the researchers involved in the project. These researchers are the only people who will have access to these files. The audiotapes and the computer will be kept under lock and key.

What will happen to the findings from this research…?

The findings from the study will be written up for publication in community reports, pamphlets, books and in academic journals.

If you have questions…

If you have any questions about the research you are very welcome to phone Shelley Mallett (Research Fellow, PhD) at The University of Melbourne on 8344 0245 or 1800 676 100. You can also email her on smallett@unimelb.edu.au.

The Ethics Committee at The University of Melbourne has given approval for this study. If you have any concerns about the way you or your child were treated during the study or queries that the researcher was not able to answer to your satisfaction please contact the Human Ethics Committee as follows:

Ms Kate Murphy
Executive Officer
Human Research Committee
Walter Boas Building
The University of Melbourne
Tel: (03) 8344 7507
Email: k.murphy@unimelb.edu.au

Information for Parents/Guardians of Recently Homeless Young People (Aged 12-17) Participating in Project i

School of Population Health
The University of Melbourne

Information and Consent
Some info about project i ....

We are a group of researchers at The University of Melbourne who are interested in why young people become homeless and what they do once they are no longer living at home. We want to learn about what young people do to get by once they leave home: who they hang out with; who gives them support and care; what services they use; and what they think about these services. We also want to understand how young people manage their health and attempt to remain safe.

We have asked your child to be part of a three year study which will involve (up to three) interviews each year. Your child will be reimbursed between $20 and $40 for doing each interview. The longer s/he stays with the project, the more s/he will be reimbursed for an interview.

Why did we ask your child to participate?

Because s/he is:

- between the ages of 12 and 17.
- S/he was asked or ordered to leave home, or left without your consent for the first time less than six months before s/he was asked to participate in the study.
- S/he may be receiving services from one of the agencies participating in the research.

Voluntary participation

Your child’s participation in this project is completely voluntary and will not effect his/her ability to receive services at any agency or organisation affiliated with the project. If s/he participates in the study s/he can refuse to answer any of the specific questions in the interviews.

What’s involved?

Your child will be asked to do up to three interviews each year with a researcher from the project. Each interview will take about two hours. During the interview s/he will be asked to complete a survey that will ask questions about his/herself, his/her background, the places s/he has lived, the people who support him/her, his/her drug use, sex life and education. S/he will also be asked about why s/he left home, his/her feelings about being homeless and how this has changed his/her life. This interview will be audiotape recorded. The audiotape recordings will be erased at the end of the project. At some stage during the research your child may also be given a disposable camera and asked to take photographs. Some of these photographs may be used in an exhibition.

Who will benefit from the research?

Studies such as this give your child an opportunity to tell us what s/he thinks about the issues that affect him/her. From this we will:

- learn about the issues for young people who are not living at home,
- learn about the different paths young people follow when they leave the family home,
- have greater understanding of the positive ways in which young people learn to look after themselves when they are not living with their families,
- learn how to assist health professionals, social workers and youth workers to help young people reduce their risk of contracting HIV and HEP C,
- learn how governments, services and health professionals can improve services to homeless young people.

Are there any risks to your child in being involved in the project?

This project will not bring any physical risks to your child. However, talking about his/her family background and his/her personal, sexual and drug using experiences may make him/her feel uneasy.

Keeping in contact...

We would like to stay in touch and interview your child up to three times a year for three years. To do this we will need to contact him/her from time to time. The researcher will ask him/her for contact information. This might include things like your child’s current address, phone number, hotmail (if s/he has one), and the contact details of a third person(s) who could put us in touch with him/her. We might also ask if we could contact him/her through a service or agency that s/he has contact with.

Any information about the whereabouts of your child or information about your child that is given by services or workers will be kept strictly confidential by the research team staff.
Project i - Statement of Informed Consent

Research: Project i
School of Population Health

Researcher: Dr Shelley Mallett (Research Fellow).

- I agree that I have read and understood the information about this study provided on the pamphlet called ‘Information for Parents/Guardians of Recently Homeless Young People (Aged 12-17) Participating in Project i’.

- I agree that I have been given a copy of this sheet and any questions I have asked have been answered to my satisfaction.

- I agree to my child’s participation in this study, knowing that I may withdraw my consent for him/her to participate at any time.

- I agree that research data collected for this study may be published or provided to other researchers on the condition that no names or other identifying characteristics will be used. I have been informed that the confidentiality of the information I provide will be safeguarded, subject to legal requirements.

Parent/Guardian

Name __________________________________________
(First name or pseudonym)

Signature________________________________________

Date____________________

Researcher

Name __________________________________________

Signature________________________________________

Date____________________
(month/day/year)
Appendix B

**Stata syntax for prevalence analyses using a generalised estimating equation**

\[ \text{xi: xtgee hcvtest covariate(s) i.time, i(subject) family(binomial) link(logit) eform} \]

**Stata syntax for generating the survival-time dataset**

\[ \text{stset interviewdate, id(subject) failure(hcvtest==1) enter(time==1) origin(time dob) scale(365.25)} \]

**Stata syntax for calculating crude rate ratios**

\[ \text{xi: glm _d i.covariate, family(poisson) link(log) lnoffset(risktime½ ) eform cluster(subject)} \]

**Stata syntax for incidence analyses using a discrete-time survival model**

\[ \text{xi: glm _d i.covariate(s) i.prevtest i.time, family(Bernoulli) link(clog) lnoffset(risktime) eform cluster(subject)} \]
Appendix C

Plain language statements and informed consent forms for semi-structured qualitative interviews with recently homeless young people.

Separate forms were provided for:

- young people aged 12-17 years
- young people aged 18 years and older
- parents of young people aged 12-17
Young People’s Health

Information for Young People (Aged 12-17)
Participating in Qualitative Interviews

The Key Centre for Women’s Health
Department of Public Health
The University of Melbourne

Some info about Young People’s Health...

The Project i researchers at The University of Melbourne and the University of California, Los Angeles are interested in what happens to young people when they leave home because of difficult circumstances. We want to learn about what young people do to get by once they leave home; who they hang out with; who gives them support and care; what services they use; and what they think about these services. We also want to understand how young people manage their health.

We invite you to participate in Young People’s Health, one part of Project i. This will involve one half-hour, semi-structured interview. You will be reimbursed $25 for doing the interview.

Why did we ask you to participate?

because you are:
• between the ages of 12 and 17, and
• already participating in Project i

What’s involved?

You will be asked to do one interview with a researcher from the project that will take about half an hour. During the interview you will be asked questions about your health, including drug use, sex life, and medical testing; the people that support you, including the services you may have used; and your current living situation. The interview will be tape-recorded and then transcribed. The tape recordings will be erased at the end of the project.

Are there any risks for me in being involved in the project?

This project will not bring any physical risks to you. However, talking about your family background and your personal, sexual, drug using and health experiences may make you feel uneasy. At the completion of the interview we will take time to see that you are feeling OK. We will also provide you with a card listing the day-time phone number and email address of Paul Myers and the Project i Research Director, and emergency telephone numbers should you need any additional support or referrals following the interview.

Voluntary participation

Your participation in this project is completely voluntary and will not affect your ability to receive services at any agency or organization affiliated with the project. If you do participate in the study you can refuse to answer any of the specific questions in the interview.

Who will benefit from the research?

Studies such as this give you an opportunity to tell us what you think about the issues that affect you. From this we will:
• learn about the issues for young people who are not living at home,
• learn about the different paths young people follow when they leave home,
• have greater understanding of the ways in which young people learn to look after themselves when they are not living with their families,
• learn how to assist health professionals, social workers and youth workers to help young people reduce their risk of contracting HIV and HEP C,
• learn how governments, services and health professionals can improve services to homeless young people.

Confidentiality—we’ll be just as careful as you…

We are interested in you and careful about what you tell us. Everything you tell us will be held confidentially and not released or disclosed without your consent, except as specifically required by law. Normally, the researchers cannot guarantee absolute confidentiality with respect to illegal behaviour of which they are made aware. If you reveal current physical or sexual abuse and/or suicidal/homicidal feelings, a report must be made and actions taken to protect you and others.

We’re careful not to put your name on any of the information you provide. The researchers will give you a pseudonym or false name and store any information that you provide under that name. We will erase the tape at the end of the study. Any names used during an interview will be replaced by pseudonyms or false names and any information that might identify you or your family and friends will be changed. Only the researchers immediately involved in this study will have access to the original information you provide. All information will be stored on computer files at a central location and these files will be protected by a password known only to the researchers involved in the project. These researchers are the only people who will have access to these files. The tapes and the computer will be kept under lock and key.

What will happen to the findings from this research…?

The findings from the study will be written up on our website, in community reports, pamphlets, and books and in academic journals. The findings from these interviews will also be written up in a PhD thesis. Young people will be able to access the findings at the end of the study.

If you have questions…

If you have any questions about the research you are very welcome to contact Paul Myers (PhD Candidate) at The University of Melbourne on (03) 8344 0245. You can also email him on pmmyers@unimelb.edu.au

You are also very welcome to phone:

Shelley Mallett, PhD
Project Director (Melbourne)
The University of Melbourne
(03) 8344 0245
smallett@unimelb.edu.au

Norweeta Milburn, PhD
Principal Investigator (Los Angeles)
University of California, Los Angeles
ph: 0011 1 (310) 794 3773
fax: 0011 1 (310) 794 8297
nmilburn@mednet.ucla.edu

The Ethics Committee at The University of Melbourne and the University of California, Los Angeles has given approval for this study. If you have any concerns about the way you were treated during the study or queries that the researcher was not able to answer to your satisfaction please contact the Human Ethics Committee as follows:

Executive Officer
Human Research Ethics
The University of Melbourne
Victoria 3010.
Tel: (03) 8344 2073
Young People’s Health

Qualitative Interviews with Young People (Aged 12-17)
Statement of Informed Consent

Researcher: Young People’s Health
The Key Centre for Women’s Health, The University of Melbourne
Center for Community Health, University of California, Los Angeles

Researcher: Paul Myers (PhD Candidate, KCWH)
Prof Doreen Rosenthal (Project i, Principal Investigator, KCWH)
Dr Shelley Mallett (Project i, Project Director, KCWH)
Dr Norweeta Milburn (Project i, Principal Investigator, CCH, UCLA)

• I agree that I have read and understood the information about this study provided on the pamphlet called ‘Young People’s Health: Information for Young People (Aged 12-17) Participating in Qualitative Interviews’.

• I have been provided with the follow-up numbers to ring should I have any difficulties arising as a result of the interview.

• I agree that I have been given a copy of this sheet and any questions I have asked have been answered to my satisfaction.

• I agree to take part in this study, knowing that I may withdraw at any time.

• I agree that research data collected for this study may be published or provided to other researchers on the condition that no names or other identifying characteristics will be used. I have been informed that the confidentiality of the information I provide will be safeguarded subject to legal requirements.

Participant

Name ____________________________
(First name or pseudonym)

Signature________________________ Date____________________

Researcher

Name ____________________________

Signature________________________ Date____________________
Some info about Young People’s Health…

The Project i researchers at The University of Melbourne and the University of California, Los Angeles are interested in what happens to young people when they leave home because of difficult circumstances. We want to learn about what young people do to get by once they leave home; who they hang out with; who gives them support and care; what services they use; and what they think about these services. We also want to understand how young people manage their health.

We invite you to participate in Young People’s Health, one part of Project i. This will involve one half-hour, semi-structured interview. You will be reimbursed $25 for doing the interview.

Why did we ask you to participate?

because you are:

• between the ages of 18 and 20, and
• already participating in Project i

What’s involved?

You will be asked to do one interview with a researcher from the project that will take about half an hour each. During the interview you will be asked questions about your health, including drug use, sex life, and medical testing; the people that support you, including the services you may have used; and your current living situation. The interview will be tape-recorded and then transcribed. The tape recordings will be erased at the end of the project.

Are there any risks for me in being involved in the project?

This project will not bring any physical risks to you. However, talking about your family background and your personal, sexual, drug using and health experiences may make you feel uneasy. At the completion of the interview we will take time to see that you are feeling OK. We will also provide you with a card listing the day-time phone number and email address of Paul Myers and the Project i Research Director, and emergency telephone numbers should you need any additional support or referrals following the interview.

Voluntary participation

Your participation in this project is completely voluntary and will not affect your ability to receive services at any agency or organization affiliated with the project. If you do participate in the study you can refuse to answer any of the specific questions in the interview.

Who will benefit from the research?

Studies such as this give you an opportunity to tell us what you think about the issues that affect you. From this we will:

• learn about the issues for young people who are not living at home,
• learn about the different paths young people follow when they leave home,
• have greater understanding of the ways in which young people learn to look after themselves when they are not living with their families,
• learn how to assist health professionals, social workers and youth workers to help young people reduce their risk of contracting HIV and HEP C,
• learn how governments, services and health professionals can improve services to homeless young people.

Confidentiality—we’ll be just as careful as you…

We are interested in you and careful about what you tell us. Everything you tell us will be held confidentially and not released or disclosed without your consent, except as specifically required by law. Normally, the researchers cannot guarantee absolute confidentiality with respect to illegal behaviour of which they are made aware. If you reveal current suicidal or homicidal feelings, a report must be made and actions taken to protect you and others.

We’re careful not to put your name on any of the information you provide. The researchers will give you a pseudonym or false name and store any information that you provide under that name. We will erase the tape at the end of the study. Any names used during an interview will be replaced by pseudonyms or false names and any information that might identify you or your family and friends will be changed. Only the researchers immediately involved in this study will have access to the original information you provide. All information will be stored on computer files at a central location and these files will be protected by a password known only to the researchers involved in the project. These researchers are the only people who will have access to these files. The tapes and the computer will be kept under lock and key.

What will happen to the findings from this research…?

The findings from the study will be written up on our website, in community reports, pamphlets, and books and in academic journals. The findings from these interviews will also be written up in a PhD thesis. Young people will be able to access the findings at the end of the study.

If you have questions…
If you have any questions about the research you are very welcome to contact Paul Myers (PhD Candidate) at The University of Melbourne on (03) 8344 0245. You can also email him on pmmyers@unimelb.edu.au

You are also very welcome to phone:

<table>
<thead>
<tr>
<th>Shelley Mallett, PhD</th>
<th>Norweeta Milburn, PhD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Project Director (Melbourne)</td>
<td>Principal Investigator (Los Angeles)</td>
</tr>
<tr>
<td>The University of Melbourne</td>
<td>University of California, Los Angeles</td>
</tr>
<tr>
<td>(03) 8344 0245</td>
<td>ph: 0011 1 (310) 794 3773</td>
</tr>
<tr>
<td><a href="mailto:smallett@unimelb.edu.au">smallett@unimelb.edu.au</a></td>
<td>fax: 0011 1 (310) 794 8297</td>
</tr>
<tr>
<td></td>
<td><a href="mailto:nnilburn@mednet.ucla.edu">nnilburn@mednet.ucla.edu</a></td>
</tr>
</tbody>
</table>

The Ethics Committee at The University of Melbourne and the University of California, Los Angeles has given approval for this study. If you have any concerns about the way you were treated during the study or queries that the researcher was not able to answer to your satisfaction please contact the Human Ethics Committee as follows:

Executive Officer
Human Research Ethics
The University of Melbourne
Victoria 3010.
Tel: (03) 8344 2073
Young People’s Health

Qualitative Interviews with Young People (Aged 18+)
Statement of Informed Consent

Research: Young People’s Health
The Key Centre for Women’s Health, The University of Melbourne
Center for Community Health, University of California, Los Angeles

Researcher: Paul Myers (PhD Candidate, KCWH)
Prof Doreen Rosenthal (Project i, Principal Investigator, KCWH)
Dr Shelley Mallett (Project i, Project Director, KCWH)
Dr Norweeta Milburn (Project i, Principal Investigator, CCH, UCLA)

- I agree that I have read and understood the information about this study provided on the pamphlet called ‘Young People’s Health: Information for Young People (Aged 18-20) Participating in Qualitative Interviews’.

- I have been provided with the follow-up numbers to ring should I have any difficulties arising as a result of the interview.

- I agree that I have been given a copy of this sheet and any questions I have asked have been answered to my satisfaction.

- I agree to take part in this study, knowing that I may withdraw at any time.

- I agree that research data collected for this study may be published or provided to other researchers on the condition that no names or other identifying characteristics will be used. I have been informed that the confidentiality of the information I provide will be safeguarded subject to legal requirements.

Participant

Name _________________________
(First name or pseudonym)

Signature_______________________ Date____________________

Researcher

Name _________________________

Signature________________________ Date____________________
Some information about Young People's Health...

The Project i researchers at The University of Melbourne and the University of California, Los Angeles are interested in what happens to young people when they leave home because of difficult circumstances. We want to learn about what young people do to get by once they leave home; who they hang out with; who gives them support and care; what services they use; and what they think about these services. We also want to understand how young people manage their health.

We would like to invite your child to participate in Young People's Health, one part of Project i. This will involve one half-hour interview. Your child will be reimbursed $25 for doing the interview.

What am I agreeing to?

We are asking you to agree to allow your child to participate in this interview. We are asking for your permission because your child is under 18 years of age and currently living at home. If you do not wish your child to participate, we will not conduct the interview. You may also withdraw your consent for your child to do the interview at anytime.

Why did we ask your child to participate?

Because your child is:
- between the ages of 12 and 17, and
- already participating in Project i

What’s involved?

Your child will be asked to do one interview with a researcher from the project that will take about half an hour. During the interview your child will be asked questions about their health and how they spend their time. This interview will be tape-recorded and then transcribed. The tape recordings will be erased at the end of the project.

Are there any risks for my child in being involved in the project?

This project will not bring any physical risks to your child. However, talking about his/her health and how he/she spends their time may make him/her feel uneasy. At the completion of the interview the interviewer will take time to see that your child is feeling OK. We will also provide your child with a card listing the day-time phone number and email address of Paul Myers and the Project i Research Director, and emergency telephone numbers should they need any additional support or referrals following the interview.

Voluntary participation

Your child’s participation in this project is completely voluntary. They may stop doing the interview at any time and/or may refuse to answer any of the specific questions in the interview.
Who will benefit from the research?

Studies such as this give your child an opportunity to tell us what he or she thinks about the issues that affect him or her. From this we will:

- learn about the issues for young people who are not living at home,
- learn about the different paths young people follow when they leave home,
- have greater understanding of the ways in which young people learn to look after themselves when they are not living with their families,
- learn how to assist health professionals, social workers and youth workers to help young people reduce their risk of contracting HIV and HEP C,
- learn how governments, services and health professionals can improve services to homeless young people.

Confidentiality—we’ll be just as careful as you…

We are interested in your child and careful about what s/he tells us. Everything s/he tells us will be held confidentially and not released or disclosed without his/her consent, except as specifically required by law. Normally, the researchers cannot guarantee absolute confidentiality with respect to illegal behavior of which they are made aware. If your child reveals current physical or sexual abuse and/or suicidal/homicidal feelings, a report must be made and actions taken to protect him or her and others.

This interview is confidential and, as a result, you will not be able to be present during the interview or have access to what your child says during the interview.

We’re careful not to put your child’s name on any of the information he or she provides. The researchers will give your child a pseudonym or false name and store any information that is provided under that name. Any names used during an interview will be replaced by pseudonyms or false names and any information that might identify your child or your family and friends will be changed. Only the researchers immediately involved in this study will have access to the original information provided. All information will be stored on computer files at a central location and these files will be protected by a password known only to the researchers involved in the project. These researchers are the only people who will have access to these files. The tapes and the computer will be kept under lock and key.

What will happen to the findings from this research…?

The findings from the study will be written up on our website, in community reports, pamphlets, and books and in academic journals. The findings from these interviews will also be written up in a PhD thesis. Your child will be able to access the findings at the end of the study.

If you have questions…

If you have any questions about the research you are very welcome to contact Paul Myers (PhD Candidate) at The University of Melbourne on (03) 8344 0245. You can also email him on pmmyers@unimelb.edu.au

You are also very welcome to phone:

**Shelley Mallett, PhD**  
Project Director (Melbourne)  
The University of Melbourne  
(03) 8344 0245  
smallett@unimelb.edu.au

**Norweeta Milburn, PhD**  
Principal Investigator (Los Angeles)  
University of California, Los Angeles  
ph: 0011 1 (310) 794 3773  
fax: 0011 1 (310) 794 8297  
nmilburn@mednet.ucla.edu

The Ethics Committee at The University of Melbourne and the University of California, Los Angeles has given approval for this study. If you have any concerns about the way you were
treated during the study or queries that the researcher was not able to answer to your satisfaction please contact the Human Ethics Committee as follows:

Executive Officer  
Human Research Ethics  
The University of Melbourne  
Victoria 3010.  
Tel: (03) 8344 2073
Young People’s Health

Parents or Guardians of Young People

Statement of Informed Consent

Research: Young People’s Health
The Key Centre for Women’s Health, The University of Melbourne
Center for Community Health, University of California, Los Angeles

Researcher: Paul Myers (PhD Candidate, KCWH)
Prof Doreen Rosenthal (Project i, Principal Investigator, KCWH)
Dr Shelley Mallett (Project i, Project Director, KCWH)
Dr Norweeta Milburn (Project i, Principal Investigator, CCH, UCLA)

- I agree that I have read and understood the information about this study provided on the pamphlet called ‘Young People’s Health: Information for Parents or Guardians of Young People Participating in Qualitative Interviews’.

- I agree that I have been given a copy of this sheet and any questions I have asked have been answered to my satisfaction.

- I agree to my child’s participation in this study, knowing that I may withdraw my consent at any time.

- I agree that I will not be able to be present during the interview or have access to what my child says during the interview.

- I agree that research data collected for this study may be published or provided to other researchers on the condition that no names or other identifying characteristics will be used. I have been informed that the confidentiality of the information I provide will be safeguarded subject to legal requirements.

Parent/Guardian

Name _________________________ (First name or pseudonym)

Signature_______________________ Date_____________________

Researcher

Name _________________________

Signature________________________ Date_____________________