

Safety in the silence: Hepatitis C risk and prevention in three networks of Australians who inject drugs

Author:

Newland, Jamee

Publication Date:

2015

DOI:

<https://doi.org/10.26190/unsworks/18198>

License:

<https://creativecommons.org/licenses/by-nc-nd/3.0/au/>

Link to license to see what you are allowed to do with this resource.

Downloaded from <http://hdl.handle.net/1959.4/54476> in <https://unsworks.unsw.edu.au> on 2024-05-02

Safety in the silence: Hepatitis C risk and prevention in three networks of Australians who inject drugs

Jamee Newland



Submitted in fulfillment of the requirements for the degree of
Doctor of Philosophy
Centre for Social Research in Health
University of New South Wales
May 2015

Copyright, authenticity and originality statement

Copyright statement: I hereby grant to the University of New South Wales (UNSW) or its agents the right to archive and to make available my thesis or dissertation in whole or part in the University libraries in all forms of media, now or hereafter known, subject to the provisions of the Copyright Act 1968. I retain all proprietary rights, such as patent rights. I also retain the right to use in future works (such as articles or books) all or part of this thesis or dissertation. I also authorise University Microfilms to use the abstract of my thesis in Dissertations Abstract International. I have either used no substantial portions of copyright material in my thesis or I have obtained permission to use copyright material; where permission has not been granted I have applied/will apply for a partial restriction of the digital copy of my thesis or dissertation.

Authenticity Statement: I certify that the Library deposit digital copy is a direct equivalent of the final officially approved version of my thesis. No emendation of content has occurred and if there are any minor variations in formatting, they are the result of the conversion to digital format.

Originality statement: I hereby declare that this submission is my own work and to the best of my knowledge it contains no materials previously published or written by another person, or substantial proportions of material which have been accepted for the award of any other degree or diploma at UNSW or any other educational institution, except where due acknowledgement is made in the thesis. Any contribution made to the research by others, with whom I have worked at UNSW or elsewhere, is explicitly acknowledged in the thesis. I also declare that the intellectual content of this thesis is the product of my own work, except to the extent that assistance from others in the project's design and conception or in style, presentation and linguistic expression is acknowledged.

Signed Date

Abstract

Hepatitis C is a significant public health issue in Australia, as it is in many countries around the world. In the last few years, the field of social research on hepatitis C has expanded to more explicitly acknowledge and address the broad range of factors that influence health and risk in the context of hepatitis C transmission. Rhodes' (2002, 2009) 'risk environment framework' has been particularly influential in this regard, identifying policy, economic, physical and social environments that operate at micro- and macro-levels of influence. However, little research has explored in detail the 'micro-social' dimensions of hepatitis C risk and prevention. Employing a social network analysis design, combining qualitative interviews and participatory social network mapping, this study generated new insights into how social network factors influenced the sharing and reuse of injecting equipment within particular networks of people who inject drugs. The networks were recruited from three geographically and socially diverse settings in Australia. The first network was located in inner city Sydney, an area with a demographically diverse population; the second in outer suburban Sydney, in an area with high numbers of Vietnamese migrant Australians; and the third in a regional city in New South Wales, in an area with high numbers of economically marginalised young people. The analysis focused on exploring the different perspectives shared by network members regarding hepatitis C-related knowledge, communication and network dynamics. A pervasive silence was observed in all networks regarding hepatitis C, accompanied by remarkable variation in knowledge of hepatitis C between network members. However, despite this range in knowledge and restriction in communication, evidence was also found of network members actively working to prevent hepatitis C transmission in their networks, particularly through peer distribution of sterile injecting equipment. Nonetheless, the normalisation of hepatitis C within these networks of people who inject drugs did not necessarily result in a reduction in hepatitis C-related stigma. Further research is needed to consider how these related social network-level factors influence hepatitis C transmission in a diverse range of other networks of people who inject drugs, to strengthen the potential for harm reduction approaches to acknowledge and learn from these 'informal' responses to hepatitis C risk.

Acknowledgements

Several people and institutions have been instrumental in the various phases of this doctoral thesis. Firstly, this study would not have occurred were it not for the study participants themselves and the many services that assisted the study: although you cannot be individual named, thank you. Without the support, mentorship and patience of my UNSW academic supervisors; Professor Carla Treloar (UNSW, CHSR), and Dr Christy Newman (UNSW, CHSR), and pre-retirement by Professor Ralph Hall (UNSW, FASS), this doctoral thesis would never have existed. I am also thankful to for the discussions with Sam Freidman at the International Harm Reduction Association Conference in Liverpool that helped me come to terms with network data. Professor Carla Treloar, Dr Christy Newman and Dr David Rollison also provided comments, edits and suggestions on the draft of this thesis. I also want to acknowledge my father, John Newland, who reproduced all the network diagrams in this thesis, and my mum and Ann Whitelaw for everything these fantastic women contributed during my candidature. Acknowledgement of the institutional supports from the University of New South Wales (UNSW), including the strategic fund scholarship awarded to completed this doctoral research and supports from the Faculty of Arts & Social Sciences (FASS) and FASS essential research costs and funds for conference travel (specific conferences identified in Appendix A). During my candidature I received the Junior Researcher Support Award from the Australasian Society for HIV Medicine (ASHM), which made it possible to present this study's preliminary results at the Australasian Viral Hepatitis Conference in Melbourne in 2010. Lastly, this thesis is dedicated to my brother-in-law, who passed in January 2014, vale John Cross.

Acronyms

ABC	Australian Broadcasting Corporation
ACT	Australian Capital Territory
AGDHA	Australian Government Department of Health and Ageing
AIDS	Acquired immunodeficiency syndrome
AIVL	Australian Injecting and Illicit Drug Users League
BBV	Blood Borne Virus
CSRH	Centre for Social Research in Health
DoCS	NSW Department of Community Services
FASS	Faculty of Arts and Social Science
HCC	hepatocellular carcinoma
HCV RNA	hepatitis C virus ribonucleic acid
HIV	Human immunodeficiency virus
HREC	Human Research Ethics Committee
IHRA	International Harm Reduction Association
MACASHH	Ministerial Advisory Committee on AIDS, Sexual Health and Hepatitis C Sub-Committee
NCHSR	National Centre in HIV Social Research
NCHECR	National Centre in HIV Epidemiology and Clinical Research
NSP	Needle and Syringe Program
NSW	New South Wales
NUAA	NSW Users and AIDS Association
PCR	Polymerase chain reaction
PWID	People Who Inject Drugs
RDS	Respondent Driven Sampling

UNAIDS	United Nations Joint Program on HIV/AIDS
UNDOC	United Nations Office of Drugs and Crime
UNSW	University of New South Wales
WHO	World Health Organisation

Table of Contents

Copyright, authenticity and originality statement	i
Abstract	ii
Acknowledgements	iii
Acronyms	iv
Table of Contents	vi
List of tables and diagrams	xi
Chapter 1 Introduction	1
1.1 Background to the problem	2
1.2 Statement of the problem	4
1.3 Aim of the study	5
1.4 Design and methods.....	6
1.4.1 Qualitative social network analysis.....	7
1.4.2 Peer distribution sub-analysis.....	9
1.5 Chapter Outline.....	10
1.6 Notes on language and representation	11
Chapter 2 Background to the study.....	13
2.1 Biomedical understandings of hepatitis C	13
2.1.1 Hepatitis C: transmission	14
2.1.2 Hepatitis C: the virus.....	15
2.1.3 The natural history of hepatitis C.....	16
2.1.4 Biomedical responses to hepatitis C.....	18
2.2 Social understandings of hepatitis C.....	19
2.2.1 The policy environment	21
2.2.1.i Availability and coverage of clean needles and syringes	22
2.2.1.ii Policy and law reform	24
2.2.2 The economic environment.....	25
2.2.2.i Social disadvantage.....	26

2.2.2.ii	Provision of low-threshold services	27
2.2.2.iii	Balancing investment in harm reduction programs and law enforcement	27
2.2.3	The physical environment.....	29
2.2.3.i	Policing practice	29
2.2.3.ii	Drug using places	30
2.2.3.iii	Place as enabling.....	31
2.2.4	The social environment.....	31
2.2.4.i	Stigma and marginalisation.....	33
2.2.4.ii	Mass media and awareness campaigns	36
2.2.5	Understanding the role of the social network in hepatitis C transmission	36
2.2.5.i	Social network membership and transmission risk	36
2.2.5.ii	Social dynamics in the sharing and reusing of injecting equipment.....	39
2.2.5.iii	Social networks as enabling	43
2.2.5.iv	Informal peer-based communication	46
2.2.5.v	Peer distribution (secondary exchange)	49
2.3	Concluding remarks	51
Chapter 3 Research design & methodology.....		54
3.1	Research design	54
3.1.1	Theoretical orientation	54
3.1.2	Conceptual framework	57
3.1.2.i	i The networks.....	60
3.2	Social network analysis methodology.....	60
3.2.1	Social network study sites.....	60
3.2.2	Social network sampling and recruitment	61
3.2.3	Data collection	64
3.2.3.i	Semi-structured interviews.....	64
3.2.3.ii	Participatory social network mapping	65
3.2.3.iii	Field notes and observations	66
3.2.4	Data analysis	66

3.2.4.i	Thematic analysis	67
3.2.4.ii	Relational analysis	67
3.3	Peer distribution sub-analysis	69
3.3.1	Sampling and recruitment	70
3.3.2	Thematic data analysis	70
3.3.3	Identifying case studies	71
3.4	Ethical considerations	72
3.5	Summary	74
Chapter 4	Newcastle network.....	76
4.1	Study site overview	76
4.1.1	The setting.....	76
4.1.2	Recruitment	78
4.1.3	The main network members.....	79
4.1.4	The network relationships	81
4.2	Hepatitis C-related understandings	83
4.2.1	Knowledge about hepatitis C	83
4.2.2	Beliefs about the seriousness of hepatitis C	88
4.3	Hepatitis C-related communication	91
4.3.1	Absence of hepatitis C discussions.....	92
4.3.2	Absence of hepatitis C antibody disclosure discussions	95
4.4	Social network dynamics in the injecting environment.....	100
4.4.1	Network breakdown	100
4.4.2	Injecting hierarchy	101
4.4.3	Injecting equipment practices	104
4.4.4	Image management and blending in	109
4.4.5	Self-harming as a hepatitis C transmission route	109
4.5	Summary of the Newcastle network	110
Chapter 5	South-West Sydney network	113
5.1	Study site overview	113
5.1.1	The setting.....	113
5.1.2	Recruitment	115

5.1.3	The main characters.....	116
5.1.4	The network relationships	119
5.2	Hepatitis C-related understandings	121
5.2.1	Knowledge about hepatitis C	121
5.2.2	Beliefs about the seriousness of hepatitis C	124
5.3	Hepatitis C-related communication	128
5.3.1	Absence of discussions about hepatitis C	128
5.3.3	Absence of discussions about hepatitis C status	131
5.4	Social network dynamics in the injecting environment.....	137
5.4.1	Injecting roles and hierarchies	137
5.4.2	Only inject with each other and not in public.....	139
5.4.3	Cleaning used injecting equipment.....	141
5.4.4	Hiding drug use from family and community	142
5.4.5	Image management and blending in	144
5.4.6	Exclusion from the injecting environment as a response to hepatitis C.....	146
5.4.7	Exclusion from social networks as a response to hepatitis C	146
5.5	Summary of the South-West Sydney network.....	148
Chapter 6 South-East Sydney network		151
6.1	Study site overview	151
6.1.1	The setting.....	151
6.1.2	Recruitment	153
6.1.3	The main characters.....	153
6.1.4	The network relationships	157
6.2	Hepatitis C-related understandings	159
6.2.1	Knowledge about hepatitis C	159
6.2.2	Beliefs about the seriousness of hepatitis C	165
6.3	Hepatitis C-related communication	169
6.3.1	Absence of hepatitis C discussions.....	169
6.3.3	Discussing specific or detailed issues related to hepatitis C	172
6.3.2	Disclosure of hepatitis C antibody status.....	177
6.4	Social network dynamics in the injecting environment.....	180
6.4.1	Injecting roles and hierarchies	180
6.4.2	Always using sterile injecting equipment	183

6.4.3	The breakdown of network relationships	186
6.5	Summary of the South East Sydney network.....	188
Chapter 7	Peer distribution	191
7.1	Overview	191
7.2	Peer distribution activity and rationale	192
7.2	Peer distribution roles	193
7.2.2.i	Formal peer distributor case studies	194
7.2.2.1.i	Jayde (F17) Newcastle.....	195
7.2.2.1.ii	Chris (M21) Newcastle	198
7.2.2.1.iii	Natasha (F39) Newcastle	199
7.2.2.1.iv	Kevin (M47) South-East Sydney	200
7.2.2.1.v	Emma (F43) NSW North Coast	202
7.2.2	Informal peer distribution roles and pathways	204
7.2.2.i	Reciprocal exchange between close friends and family	204
7.2.2.ii	Reciprocal exchange between people living in close proximity to each other.....	207
7.2.2.iii	Distribution between dealers and their customers.....	210
7.2.2.iv	Distribution between acquaintances	211
7.2.3	Legal implications of peer distribution	213
7.2.3.i	Confusion about legal and policy issues	214
7.2.3.ii	Notions of altruism.....	215
7.2.3.iii	Low perceived risk of legal implications	216
7.2.3.iv	Conflict with the goals of harm reduction	217
7.3	Concluding remarks	218
Chapter 8	Discussion	221
8.1	Making sense of hepatitis C understandings within diverse networks of people who inject drugs	226
8.2	Negotiating the general silence surrounding hepatitis C within injecting networks	235
8.3	Appreciating the challenges of disclosing a positive hepatitis C status within injecting networks	239

8.4	Reproducing stigma and inequality within social networks of people who inject drugs ...	242
8.5	Responding to the micro-social dynamics of hepatitis C risk in social networks	246
8.6	Legitimising peer-led responses to hepatitis C risk reduction	253
8.7	Methodological reflections	257
8.8	Concluding remarks	262
References		266
Appendix A	Associated conference presentations	296
Appendix B	Interview Schedule	297
Appendix C	Human Research Ethics Clearance (HREC 09022)	299
Appendix D	HREC (09022) amendment	301
Appendix E	Participant socio-demographics	304

List of tables and diagrams

Diagram 1	Newcastle social network and sub-groups	82
Diagram 2	South-West Sydney social network and sub-groups	120
Diagram 3	South-East Sydney social network and sub-groups	157
Table 1	Formal peer distributor size and outreach	195

Chapter 1 Introduction

Although social contexts are routinely identified as being among the more important determinants of human interaction (Bourdieu & Wacquant, 1992; Neaigus, Friedman, Kottiri, & Des Jarlais, 2001), social relationships as a specific site of influence in hepatitis C transmission risk and prevention have received little attention in the research literature. This lack of attention means that the social network factors that influence the transmission and prevention of hepatitis C are not well understood and therefore are not able to be addressed through policy and practice (Latkin & Knowlton, 2005; Rhodes, Singer, Bourgois, Friedman, & Strathdee, 2005; Rhodes & Treloar, 2008).

Reporting on qualitative research conducted with three social networks of Australians who inject drugs (PWID) in the state of New South Wales (NSW), including the geographical regions known as Newcastle, South-West Sydney, South-East Sydney, this study aims to address the gap in knowledge regarding the social network as a specific site of influence in hepatitis C transmission and prevention. Using a qualitative social network analysis design, including a qualitative thematic approach to analysing interview data alongside participatory approaches to social network mapping, this study has paid particular attention to documenting hepatitis C-related understandings and how this knowledge was communicated within the three groups of linked participants who took part in the study. Attention was also paid to identifying and describing different social network dynamics that may influence hepatitis C prevention, particularly with respect to the procurement, preparation and consumption of drugs. The most prominent network practice reported by participants in this study was the distribution of sterile injecting equipment to other network members. Given the significant influence that the practice of distributing sterile injecting equipment within the networks of PWID could have on hepatitis C transmission risk, a sub-analysis was then conducted on this practice.

This study therefore advances understandings of the micro-social level of influence on hepatitis C risk and prevention, particularly with respect to the way the hepatitis C is understood, communicated and responded to in populations of PWID, which has implications both for the academic body of literature and harm reduction responses. This chapter provides background to the study and a statement of the problem that the thesis is intending to address, namely to acknowledge and assess the influence of the social network influence on hepatitis C transmission risk and prevention. The aims of the study, and associated research questions, are also discussed, and the chapter concludes with a brief description of the qualitative social network analysis design employed in this study along with an overview of the chapter outline.

1.1 Background to the problem

Hepatitis C is a blood-borne virus (BBV) that is transmitted through blood-to-blood contact (Dore, 2001). Although there are still issues under debate in relation to the epidemiology and natural history of hepatitis C (Fraser & Seear, 2011; Seeff, 2002), it is widely agreed that this virus affects the liver which can lead to inflammation, scarring, cirrhosis, hepatocellular carcinoma (liver cancer) and – in an increasing number of people – death. As hepatitis C viral progression is largely asymptomatic (Maasoumy & Wedemeyer, 2012), through which it can take some years or even decades before negative health effects become apparent, hepatitis C is often described in the literature as a ‘silent epidemic’ (Carrier, Laplante, & Bruneau, 2005; Harsch et al., 2000; World Health Organisation, 2012a, 2012b), ‘silent pandemic’ (Economic Intelligence Unit, 2013) and a ‘silent infection and time bomb’ (Cohen, 1999).

Despite this silence, hepatitis C is increasingly recognised as a significant and growing public health crisis, both in Australia and internationally. It is estimated that there are 160 to 170 million people who are infected with hepatitis C around the world (Maasoumy & Wedemeyer, 2012; Shepard, Finelli, & Alter, 2005) and it is thought that this number increases by three to four million people per

year (World Health Organisation, 2012b). It is also estimated that 350,000 people will die every year as a result of hepatitis C liver-related complications (Perz, Armstrong, Farrington, Hutin, & Bell, 2006; World Health Organisation, 2012b). In 2011, it was estimated that 304,000 people in Australia were believed to have been exposed to hepatitis C and 226,700 people were living with chronic hepatitis C (The Kirby Institute, 2012). Of the latter group, 170,000 people were estimated to have early liver disease, 49,500 to have moderate liver disease and 6,300 to be living with hepatitis C-related cirrhosis (The Kirby Institute, 2012).

The long-term health outcomes resulting from chronic hepatitis C infection are placing increasing burdens on the health care system. For example, at the time of writing, hepatitis C was the leading cause of liver transplantation in developed countries (Grebely & Dore, 2011a) and hepatitis C-related deaths have, for the first time, surpassed those of HIV in Australia (Dore, 2012; Grebely & Dore, 2011a) and the United States (Holmberg et al., 2012; Klevens, Hu, Jiles, & Holmberg, 2012). These health impacts will also be accompanied by significant social and budget considerations. Current spending on hepatitis C by Australian state, territory and Commonwealth Government departments is AUD\$242m annually and as the burden of hepatitis C-related illness increases this spending is projected to grow to at least AUD\$ 1.5b over the next five years (The Boston Consulting Group, 2012).

Since hepatitis C surveillance began in Australia over two decades ago, the sharing and reuse of injecting equipment has been implicated in over 90% of all new hepatitis C infections (Palmateer et al., 2010) and although there has been a recent decline in new hepatitis C notifications in Australia, approximately 10,000 new infections are estimated to occur annually (The Kirby Institute, 2012). In response, concerted (but not optimal or universal) national harm reduction responses have been implemented to reduce hepatitis C transmission within PWID populations, primarily through provision of sterile injecting equipment in Needle Syringe Programs (NSPs). However, research

suggests that social context is also significant in injecting equipment sharing and reuse, even in areas regarded as having a high level of equipment coverage (Bryant, Paquette, & Wilson, 2012; Mateu-Gelabert et al., 2007; Rhodes, Davis, & Judd, 2004; Rhodes et al., 2005; Rhodes & Treloar, 2008; Rhodes et al., 2012). Therefore, new knowledge is required to better understand those social contexts and conditions that encourage, or prevent, equipment sharing and reuse in an attempt to more effectively respond to hepatitis C transmission risk.

1.2 Statement of the problem

The vulnerability that places individual PWID at risk of drug harm (or protection) is not only influenced by knowledge and beliefs about an issue, such as hepatitis C: research also suggests that drug use, and associated harm, is also contingent upon social context (Rhodes, 2009). Scholars in the field have called for a move away from understanding drug-related harm from the perspective of the individual, where it is suggested that behaviour is based solely on individual choice (Ramos et al., 2009), to social-level factors (Rhodes et al., 2012; Strathdee et al., 2010), which shifts focus away from individual factors to understanding hepatitis C transmission risk in terms of social context (Rhodes, 2002, 2009). The response to these calls has been an increasing use of the risk environment framework in research. However, reporting on the risk environment has to date tended to still rely upon employing the individual as the unit of analysis and therefore this approach has been less well placed to appreciate and explore the social relationship dynamics between PWID as a specific and significant site of influence on hepatitis C transmission risk. This level of influence, which Rhodes' describes as the 'micro-social' environment, can be defined as the place "where people spend the vast majority of their lives, living and interacting with the small groups that make up the world around them" (Trotter, 1999, p. 7).

1.3 Aim of the study

In this thesis, it is argued that to gain a better understanding of the social and environmental factors that increase or decrease transmission risk, there is a need to further explore how the micro-social environment influences hepatitis C transmission risk and prevention. Therefore, this study aims to draw attention to social networks of PWID as a specific site of influence: both in order to reveal new opportunities to explore this level of influence within the risk environment framework literature, and to generate new understandings of the specific micro-social contexts and dynamics that may positively or negatively influence hepatitis C transmission risk. At the outset it also important to note that the aim of this study is to focus solely on perceptions of and responses to hepatitis C risk, and therefore did not seek to understand social perspectives on HIV or hepatitis B, as other important blood borne viruses. This focus was influenced by the setting in which this study was conducted (Australia), which mobilised an early and effective response to preventing HIV transmission among people who inject drugs (Bernard, Kippax, & Baxter, 2008; Madden & Wodak, 2014), especially when compared with the US and the UK where prevalence and incidence of HIV are significantly higher. The numbers of people who have been infected with HIV via the sharing of injecting equipment is therefore very small, and is not as great a risk for this population as hepatitis C. Hepatitis B is also found in much lower numbers among this population. In the Australian context, the very great focus on HIV has led some scholars to suggest that there is a form of “HIV/AIDS exceptionalism” (Islam, Day, & Conigrave, 2010) operating which can influence, and sometimes marginalise, responses to other blood-borne viruses, such as hepatitis C and B. Therefore the focus on hepatitis C within this study was perceived to be important; not only due to research novelty but also because of important situational and environmental influences that were seen impact individual and network responses to hepatitis C in particular. However, the methods and results from this thesis may potentially assist in informing the development of future research on individual and social network understandings and responses to other blood-borne viruses, such as HIV and hepatitis B. The rest of

this section will summarise the qualitative social network study design and methods, including the two analyses conducted and the different sampling and research questions posed.

1.4 Design and methods

This study utilised a social network analysis design drawing on qualitative methods (henceforth referred to as qualitative social network analysis) to document, analyse and make inferences about the social network-level of influence on study's core objectives, that is hepatitis C-related understandings, communication and network dynamics, in a diverse range of geographic settings in NSW, Australia. Social network analysis is best described as a set of theories, methods, applications or approaches that focus on relationships among social entities (Knoke & Yang, 2007) and the focus of a social network inquiry consists of the identification of a set of network members, the social relations between them and the influence of these relationships on a specific area of study (Wasserman & Faust, 1994). In this research, I was interested in exploring the influence of social network-level factors in hepatitis C prevention and risk, paying particular attention to how hepatitis C was understood by individual network members and subsequently communicated and responded to within the networks of participants. To explore these network factors, a number of research questions were developed to focus the broad aims of the research onto a number of core domains, specifically:

- What individual-level understandings regarding hepatitis C risk and prevention were evident in each social network?
- What forms of hepatitis C-related communication were reported to operate within these networks? What was the nature of discussions about hepatitis C, who did they occur between, and in what context?
- Were there particular social network dynamics reported by network participants, which could be viewed to influence hepatitis C transmission risk and prevention?

- What lessons for hepatitis C research and prevention were learnt from this qualitative social network analysis of networks of people who inject drugs?

1.4.1 Qualitative social network analysis

Although social network analysis has tended to be dominated by quantitative approaches, “the definition of social network analysis does not presuppose a particular method for exploring patterns of network relations” (Heath, Fuller, & Johnston, 2009, p. 647). On the contrary, a number of scholars have noted that qualitative approaches to social network analysis are both possible and valuable, yet this is for very different reasons to quantitative approaches, since each of these distinctive approaches would “deal with *different features* of networks; either ‘structure’ (quantitative methods) or ‘process’ (qualitative methods)” (Crossley 2009a, 6). Thus, it is essential to understand that in this research, the focus is very much on understanding the social processes inherent to hepatitis C risk and prevention within networks of individuals who inject drugs, rather than documenting the structure of those networks.

Within a qualitative social network approach, understanding network processes (Heath et al., 2009; Heath, Fuller, & Johnston, 2010) is achieved by examining the situated enactment of these processes through insider perspectives, or a range of subjective viewpoints (Knox, Savage, & Harvey, 2006). It has also been reported that “qualitative social network analysis has been less interested in resource exchange and more interested in exploring the ‘lived experience’ of social networks” (Emmel & Clarke, 2009, p. 2). Therefore, qualitative social network analysis will often generate observational, narrative, and visual data on social relations to reveal particular insights about how social networks operate. This data can be collected using in-depth interviews (Pahl & Spencer, 2004) and participatory mapping techniques (Emmel, 2008) and analysed using content and thematic analysis (Emmel & Clarke, 2009). In contrast, quantitative social network analysis is more concerned with describing and making sense of the interconnectedness of whole networks, and with generating

numerical data to measure structures within those networks, through, among other techniques, allocating scores to evaluate the strength of different relationships within a network (Knox et al., 2006). Due to the qualitative focus of the social network analysis undertaken for this study, quantitative social network analysis practices, including measurement and scoring of power relations within networks, were not incorporated.

Although there is a growing body of evidence that reports on the use of qualitative social network analysis (Alexander, 2009), to the best of my knowledge, a qualitative social network approach has not been previously employed, or at least published, in the hepatitis C social research literature. The focus of this study, reported through individual accounts of decision-making, or understandings, was important because it was these individual accounts, when situated within a network approach, which permitted an exploration of similarities and differences in hepatitis C-related understandings, communication and network responses (Heath et al., 2009). As previously described, particular attention was paid to identifying and describing the different social network contexts that may have played a role in influencing hepatitis C risk and prevention within the networks, with a particular focus on documenting the differences in hepatitis C-related knowledge and understandings between network members, as well as the different social network dynamics that influence the procurement, preparation and consumption of drugs (referred to as network dynamics in this thesis). The interview questions explored in the following key issues and experiences of participants:

- Who have you interacted, injected or socialised with recently ? [social network mapping]
- Are there people who you previously used to interact, inject or socialise with but no longer do? Why ? [network breakdown and change]
- In your network, what do you typically talk about and with whom? [communication processes]
- In your network, do you talk about hepatitis C, in what context and with whom?

- Can you describe a typical injecting episode, including people present, and roles in sourcing, preparing and consuming drugs and accessing injecting equipment?

The social networks reported in this study were recruited from three geographically diverse networks of Australians who inject drugs, including the geographical regions known as Newcastle, South-West Sydney, South-East Sydney. The rationale for selecting distinctive geographical study sites was based on the premise that “drug use always takes place within specific cultural settings where the setting itself often influences the ways in which risks are experienced” (Duff, 2003, p. 286). Specific cultural settings result in different network structures, drug using practices, economies of drug production, distribution and consumption, socio-demographic characteristics of people who use drugs, and availability and access to services for people who inject drugs. A fourth network, located in the NSW North Coast, was originally recruited into the study, however, due to the substantial breadth of data collected across the range of networks, the data collected from the NSW North Coast site has only been included in the peer distribution sub-analysis, and does not feature in a stand-alone chapter, as do the other three networks.

1.4.2 Peer distribution sub-analysis

During the data collection phase, it became evident that an important and little documented practice was occurring within each of the networks that had the potential to reduce the risk of hepatitis C transmission. This practice was peer distribution, which is the term employed here to describe the embedded practice of distributing and receiving sterile injecting equipment within networks of PWID. Using qualitative thematic analysis, the scope of the analytic framework of this research was therefore expanded to explore the practice of peer distribution occurring in the study sites, including evidence of cultures and practices influencing the adoption of particular roles in peer distribution and in navigating different social network relationship pathways through which peer

distribution occurred. The research questions addressed in the peer distribution sub-analysis included:

- What roles did individual PWID assume in peer distribution practice?
- Were specific relationship pathways evident in peer distribution?
- Could peer distribution activity be measured?
- Were study participants aware that it is illegal to participate in peer distribution in NSW?

1.5 Chapter Outline

This thesis is organised into eight chapters. Chapter 2 will outline the background to the study, including a review of the relevant literature. This chapter has been designed to highlight, in particular, the different biomedical and social understandings and approaches to hepatitis C risk and prevention. With respect to the social understandings of hepatitis C, this chapter will follow Rhodes' risk environment framework to review those policy, economic, physical and social environments that are known to influence risk and prevention. This chapter will also review the body of literature reporting on the influence of the social environment. Although the social network as a specific site of influence in the social environment has remained relatively unexplored through qualitative research to date, the quantitative field of research known as 'social network analysis' has produced a considerable number of studies on this topic. Those traditional social network analyses which have focused on HIV or hepatitis C will therefore be discussed to highlight some of the important contextual and methodological issues that were seen as particularly relevant with respect to the study's research design, data analysis and interpretation.

Chapter 3 will outline the research design and methods employed to address the research aims and questions. This chapter explains what is involved in conducting a qualitative social network analysis, as well as one guided by a risk and enabling environment conceptual approach. This chapter will then describe the two data sets collected, exploring the particular details of interest within the social

networks and in relation to peer distribution. The overriding theoretical and conceptual orientations and ethical considerations of the research are also discussed.

Chapters 4 through 6 present the three social network analysis results for the Newcastle, South-West Sydney, and South-East Sydney, respectively. Within each chapter, a general description of each study site setting is provided, including site specific recruitment processes. The main participants from each network are then introduced and their relationships to other network members explained. The results presented in these chapters have been organised according to the three key research domains described previously, reporting on hepatitis C understandings, communication and social network dynamics.

Chapter 7 will present the results from the peer distribution sub-analysis, drawing on data from all networks. Through a thematic analysis of the roles and relationship pathways relating to peer distribution practice, this chapter will reveal peer distribution to be a common and important distribution route for accessing sterile injecting equipment *within* networks of PWID. The final chapter will then discuss the main study findings, and while there is some discussion of the notable differences between the networks, this chapter is mostly focused on identifying and understanding the characteristics and dynamics which appeared to be most commonly shared across the networks. Attention in this chapter is also paid to the implications that the study findings might be seen to have for research, policy and practice.

1.6 Notes on language and representation

In this study, the term ‘people who inject drugs’ has been used as a shorthand to describe the people who very graciously gave of their time to participate in this study. Since a shorthand phrase of that kind is employed in order to be succinct, the even shorter acronym “PWID” is used quite often throughout the thesis. This representation is deliberately chosen in place of the phrase

‘injecting drug users’ (IDU), which has been critiqued as stigmatising and dehumanising because the label reduces a person solely to the practice of injecting (Australian Injecting and Illicit Drug Users League, 2006; Canadian HIV/AIDS Legal Network, 2005). Furthermore, the language of traditional, quantitative social network analysis has been very deliberately avoided in this study, due to the different assumptions and interests of a qualitative approach, and therefore study participants will not be referred to as nodes, subjects or indexes (Wasserman & Faust, 1994). Instead, participants are described as ‘participants’ as well as ‘social network members’, throughout this thesis, except when quoting directly from the quantitative social network literature. In the spirit of brevity, the phrase social networks will sometimes be truncated to simply ‘networks’. And within these networks, different social, injecting and sexual relationships will be identified for the purpose of focused analysis and discussion, where appropriate.

Chapter 2 Background to the study

The aim of this chapter is to provide some background to the study and to outline the main arguments that this thesis will address: namely the need to acknowledge and further understand social network factors, within the micro-social level of influence, in hepatitis C transmission risk and prevention. The chapter begins with an outline of biomedical understandings of hepatitis C, including a description of the virus, transmission modes and treatment. Contrasting with those biomedical accounts, the rest of the chapter reviews understandings of hepatitis C which are drawn from the social research literature, introducing the risk environment framework as a way of conceptualising those understandings. Within this section, specific attention is paid to non-individual or environmental determinants of hepatitis C transmission, including policy, economic, social and physical environments, which are seen to operate at both a micro- and macro-level of influence. A major aim of this chapter is to identify and discuss a key gap in the literature regarding the micro-social environment or more specifically, social network relationships and dynamics among PWID. The chapter concludes by describing studies that have moved beyond the level of the individual to encompass the broader and more social understandings of hepatitis C and HIV transmission as they are made known through social network relationships, to provide some the background and context for the following methodological chapter (Chapter 3).

2.1 Biomedical understandings of hepatitis C

Hepatitis C is a relatively new and extremely complex virus, first documented in the 1970's as non-hepatitis A, non-hepatitis B (Purcell, Alter, & Dienstag, 1976). In 1988, hepatitis C was first isolated and described as a specific virus (Choo et al., 1989) and it took another year, 1989, to develop the first phase of commercial diagnostic tests able to detect hepatitis C antibodies (Tedeschi & Seeff, 1995). In 2014, there are still gaps in the biomedical, epidemiological and social understandings of

hepatitis C, leading to some contestation, especially a lack of agreement regarding the natural history of hepatitis C (Chen & Morgan, 2006; Fraser & Seear, 2011; Seeff, 2002; Shepard et al., 2005). In this respect, the field of hepatitis C is said to be 'under construction' (Duffin, 2005; Fraser & Seear, 2011; Seear et al., 2012).

2.1.1 Hepatitis C: transmission

Transmission of hepatitis C occurs through blood-to-blood contact and the most strongly associated factor in the transmission of hepatitis C in Australia is the reuse and/or sharing of needles and syringes that have been previously used by someone with the hepatitis C virus (Thorpe et al., 2002). In Australia, over 90% of all new infections reported are attributed to the sharing or reuse of injecting equipment (Razali et al., 2007). Transmission has also been report to occur when blood in used needles and syringes comes into contact with other drug preparation equipment, specifically spoons, water, filters and tourniquets (Pouget, Hagan, & Des Jarlais, 2012). This other equipment may not always be used during injecting. However, due to the observational and self-report design of studies reporting on transmission from other injecting equipment, and the collapsing of all other equipment (spoons, filters, tourniquets etc.) into one category, it is not possible to isolate the transmission risk to a specific piece of other injecting equipment in hepatitis C transmission (Gillies et al., 2010).

Other hepatitis C transmission risks include needle stick injury in health care settings (Mitsui et al., 1992) and tattooing with non-sterilised needles and contaminated ink (Alter, 2002), especially in prison settings where prevalence of hepatitis C is particularly high (Butler, Lim, & Callander, 2011). Other types of body piercing have also been implicated in the transmission of hepatitis C (Alter, 2007). Mother-to-child transmission (Roberts & Yeung, 2006) and other interactions in the household, such as the sharing of razor blades, nail clippers and toothbrushes, have been shown to present very low risks for hepatitis C transmission (MacDonald, Crofts, & Kaldor, 1996). Sexual

transmission of hepatitis C has been documented (Dienstag, 2003; Terrault, 2006; The Kirby Institute, 2012) although it is believed that this mode of transmission is not as 'efficient' as for other sexually transmitted infections, such as HIV and hepatitis B (Terrault, 2006; World Health Organisation, 2012b). Furthermore, sexual transmission of hepatitis C has been more commonly reported in studies with men who have sex with men (Bradshaw, Matthews, & Danta, 2013).

Prior to 1990, blood products used in health-care settings in Australia were not screened for hepatitis C and therefore posed a risk for hepatitis C transmission (Memon & Memon, 2002). Although the introduction of hepatitis C screening of blood-donor products has eliminated this transmission mode in Australia, blood products used in health-care settings still pose a major risk for hepatitis C transmission in low income countries. For example, in 2008, only 53% of donor products were screened for hepatitis C in these countries (Emiroglu, 2010). Inadequate sterilisation and infection controls in hospitals and other health-care settings also pose a risk for hepatitis C transmission (Lavanchy, 2011). In Australia, recent cases investigated by health authorities have implicated poor infection controls and possible (large-scale) blood-borne virus transmission in a number of different health-care settings. Additionally, cosmetic procedures and religious and cultural practices, such as scarification, circumcision, acupuncture, and cupping, have also been implicated in hepatitis C transmission (Shepard et al., 2005).

2.1.2 Hepatitis C: the virus

There are at least six known genotypes and a number of genotype sub-types of the hepatitis C virus. Hepatitis C genotypes are known by numbers 1 through to 6 and the subtypes have been labelled a, b and c: named in order of their discovery (Tedeschi & Seeff, 1995). Hepatitis C is diagnosed through two tests: the first is a hepatitis C antibody test, which identifies whether a person has come into contact with hepatitis C, but will not show whether this infection is active. Current (chronic) hepatitis C infection is diagnosed through a polymerase chain reaction, a PCR test (Strader, Wright, Thomas, &

Seeff, 2004). As identified in the introduction chapter of this thesis, the global incidence, prevalence and actual genotype distribution is not known as the majority of countries do not have surveillance systems and not all people at risk have been tested for hepatitis C (World Health Organisation, 2012b). However, studies suggest that hepatitis C genotypes have a distinct geographical nature to their distribution. Genotypes 1 and 3 have a worldwide distribution, while genotypes 4 and 5 are typically found in Africa and genotype 6 is typically found in Asia (Lavanchy, 2011).

In Australia, sero-prevalence studies have shown that hepatitis C genotypes 1 (55%) and 3 (38%) are most common (McCaw, Moaven, Locarnini, & Bowden, 2003; McCaw, Moaven, Locarnini, & Bowden, 1997). However, the prevalence of genotype distribution in Australia has changed over the last two decades with a decreasing prevalence of genotype 1 and an increasing prevalence in genotype 3. Genotype 3a is the most common sub-type, which is more prevalent in younger age groups (21–40-years) compared with older age groups (41–60-years) (McCaw et al., 2003; McCaw et al., 1997). Furthermore, the prevalence and distribution of hepatitis C genotype patterns is expected to change further with different migration patterns to Australia and as commercial travel to and from Australia to other parts of the globe becomes increasingly cheaper (Rachlis et al., 2007).

2.1.3 The natural history of hepatitis C

Approximately one in four people who come into contact with hepatitis C will spontaneously clear the infection in the acute phase (Micallef, Kaldor, & Dore, 2005). This means an individual will have detectable hepatitis C antibodies but no markers of chronic infection and will therefore not develop the liver damage associated with chronic infection. However, the risk of hepatitis C re-infection after spontaneous clearance is contested in the literature. Some researchers believe those who spontaneously clear hepatitis C are at reduced risk of subsequently contracting hepatitis C again, despite ongoing exposure to hepatitis C (Grebely et al., 2006). Conversely, some have proposed that

there is no definitive proof that this is the case, and that people are therefore always at risk of re-infection (Aitken, Higgs, & Bowden, 2008).

The approximately three out of every four people who become infected with hepatitis C and do not spontaneously clear the infection will progress to chronic hepatitis C (Dore, 2012; Micallef et al., 2005). Although the individual course of hepatitis C infection is highly variable (Maasoumy & Wedemeyer, 2012; Seeff, 2002), for those who develop chronic infection it is common for their infection to follow an asymptomatic viral progression: in that it can take years or decades to produce any noticeable health outcomes. Asymptomatic progression has been documented in both the acute and chronic phases of hepatitis C (Maasoumy & Wedemeyer, 2012) and where the transition from acute to chronic hepatitis C typically occurs in the absence of symptoms (Seeff, 2002). When hepatitis C symptoms do arise, the clinical signs are unspecific (Maasoumy & Wedemeyer, 2012).

The biomedical research literature also suggests that the major factors associated with, and contributing to, rapid hepatitis C disease progression are older age and length of time of infection, and complicated by other co-morbidities that affect the liver, such as obesity (Hu et al., 2004; Marcellin, Asselah, & Boyer, 2006; Negro & Clement, 2009; Ortiz, Berenguer, Rayón, Carrasco, & Berenguer, 2002), moderate and heavy alcohol intake (Hutchinson, Bird, & Goldberg, 2005; Ostapowicz, Watson, Locarnini, & Desmond, 2003; Westin et al., 2002; Wiley, McCarthy, Breidi, McCarthy, & Layden, 2003) and HIV or hepatitis B co-infection (Jennings & Sherman, 2012; Matthews & Dore, 2008; E. Miller, McNally, Wallace, & Schlichthorst, 2012; Rockstroh & Spengler, 2004; Shepard et al., 2005). Age as a predictor of morbidity and mortality is becoming increasingly important as 20-30% of people with chronic hepatitis C will develop cirrhosis after 20 to 30 years of infection (Thein, Yi, Dore, & 2008). As the cohort of those PWID who became infected with hepatitis C in the 1970's and 80's get older and enter the period of 20-30 years post hepatitis C infection, negative health effects, such as cirrhosis, liver failure and death, as a result of chronic hepatitis C will

be increasingly observed (Thein et al., 2008). As these mortality and morbidity implications of hepatitis C are projected to increase, this infection is expected to have significant and increasing social and economic impacts over time (The Boston Consulting Group, 2012).

2.1.4 Biomedical responses to hepatitis C

Although significant investment and infrastructure has been made available for the development of a hepatitis C vaccine, to date there has been no successful trials of hepatitis C vaccine (Cox & Thomas, 2013). The main focus of biomedical responses to hepatitis C is therefore treatment. At the time of writing, hepatitis C treatment in Australia was recommended to comprise a combination of pegylated interferon and ribavirin medications. However, the uptake and impact of this treatment strategy has been somewhat limited due to relatively low treatment efficacy, side-effect profile and other significant barriers to treatment uptake. Between 1998 and 2011, it is estimated that 1-6% of Australians living with hepatitis C had ever received treatment (Iversen et al., 2014). Within an interferon-ribavirin based treatment regime, efficacy and time-frames are directly linked to hepatitis C genotypes. Among those with genotype 1, 46%–52% of patients are expected to clear the virus with a treatment timeframe of 48 weeks: while 76%–80% of those with genotype 2 or 3 are expected to clear their hepatitis C infection with a treatment timeframe of 24 weeks (Aspinall et al., 2013). Significant social, psychological and physical side-effects have been reported in a large proportion of people (Dieperink et al., 2004; Hopwood, 2013; Leutscher et al., 2010; Maasoumy & Wedemeyer, 2012; Manns, Wedemeyer, & Cornberg, 2006; Scheft & Fontenette, 2005; Zickmund et al., 2006).

In Australia there is a move towards treating hepatitis C with protease inhibitor-based treatment regimes, specifically Telaprevir and Boceprevir (known as triple therapy). These hepatitis C treatment drugs were only registered in Australia for subsidised use in early 2013 and have been shown to increase efficacy and shorten treatment duration (Dore, 2012). However, the introduction of triple therapy has also raised a number of concerns, including increased toxicity, problematic

dosing schedules and the high cost of protease inhibitors compared with other hepatitis C treatment regimes (Dore, 2012). Triple therapy has been developed to treat genotype 1 (Bacon et al., 2011), which had the lowest efficacy using an interferon and ribavirin-based treatment regime. However, these advancements will not impact on those with genotype 3, the most common genotype in Australia. Furthermore, given that this treatment regime is new, it is unclear how widely available the treatment is or if people living with hepatitis C are aware of its existence. Additionally, there have been a number of clinical trials treating people with hepatitis C without interferon (Hellard & Doyle, 2014; Sarkar & Lim, 2014) and therefore the uptake of hepatitis C treatment may also be influenced by people living with hepatitis C choosing to delay hepatitis C treatment until new non-interferon treatment options are available.

2.2 Social understandings of hepatitis C

Understandings of hepatitis C drawn from the social research literature call attention to the need to take account of the rich complexity of people's lives and in particular, those social dynamics or factors that may place an individual at an increased (or decreased) risk of hepatitis C transmission. This way of thinking requires an identification of, and response to, the social forces that shape behaviour and which therefore influence the health of drug users (Galea & Vlahov, 2002). These forces have been described in the literature as the "causes of causes – the fundamental structures of social hierarchy and the socially determined conditions these structures create in which people grow, live, work and age" (Marmot, 2007, p. 1153). As noted in the introduction to this thesis, a conceptual approach that seeks to facilitate investigation of these broader influences between an individual and their social context is that of the 'risk environment'. Conceptualised by Tim Rhodes, and taken up by an ever-increasing number of social researchers in the fields of HIV, viral hepatitis and harm reduction, the risk environment is defined as "the space – whether social or physical – in which a variety of factors interact to increase the chances of drug related harm" (Rhodes, 2002, p.

88). The harms associated with drug use, including hepatitis C transmission, are therefore viewed as a product of the social situations and environments in which they arise (Rhodes, 2009).

Within the risk environment framework, primacy is given to social context and to understanding how “the relations between individuals and environments impact on the production and reproduction of drug harms” (Rhodes, 2009, p. 193). As such, the risk environment approach is said to extend research and policy beyond the conceptualisations of risk through reference to only (individual) behavioural-level factors, in order to also take account of broader and more social understandings of risk and prevention (McNeil & Small, 2014; Rhodes, 2002, 2009). Where the focus on risk (and prevention) becomes socially situated, examining the influence of non-individual determinants, such as the social, political and economic dimensions of risk and prevention becomes crucial (Rhodes, 2002, 2009). The risk environment framework describes four potential types of environment – physical, social, economic and policy – which are seen to interact at two different levels of influence – micro and macro (Rhodes, 2002, 2009). The micro-level focuses on “personal decisions as well as the influence of community level norms and practices” (Rhodes & Simic, 2005, p. 220); whereas, the macro-level focuses on much broader and more structural factors such as stigma and discrimination, drug policy, law and policing and socio-economic disadvantage. Rhodes (2002, 2009) also acknowledges that within the risk environment framework there may be inseparability between the different environments and levels of influence and this inseparability will be discussed throughout the review.

In addressing environmental influences and hepatitis C transmission, the framework also promotes the concept of ‘enabling environments’: a strengths-based approach that focuses on the more protective and positive forces and responses to hepatitis C transmission. An enabling environment framework therefore seeks to identify the non-individual determinants that facilitate choice and enable PWID to “embrace knowledge and behaviour change to reduce drug related harm” (Moore &

Dietze, 2005, p. 275). However, it has been suggested that the literature reporting on enabling environments has “been almost entirely overlooked ... [and therefore] remains under-theorised and under-researched” (Duff, 2010, p. 338), especially when compared to the body of literature reporting on the risk environment.

As previously reported, there is an extensive literature that recognises or utilises the risk environment framework and therefore, the rest of this chapter will review a number of different economic, policy, physical and social environmental factors that have been discussed in the literature reporting on hepatitis C transmission and prevention in populations of PWID, with a particular interest in highlighting the relative lack of research available on the social networks of PWID and hepatitis C.

2.2.1 The policy environment

The policy environment operates at a number of legislative levels, including local, state, national and sometimes international levels. The influence of the policy environment also falls within and between a number of different policy portfolios, including but not limited to drug policy, health policy, employment policy and housing policy. This review cannot cover all policy domains that could be seen to influence the health and drug use of PWID but will focus on the body of literature reporting on harm reduction policy, drug policy and law reform.

Since the 1990s, harm reduction approaches have been prioritised in the prevention of hepatitis C (Commonwealth of Australia, 2011). The philosophy underpinning harm reduction is premised on the belief that it is essential to address the health and social outcomes of drug use, without the expectation these responses would (necessarily) reduce drug use (Lines & Elliott, 2007; Nadelman, McNeely, & Drucker, 1977; Wodak, 1997). This approach accepts that a drug free society is unachievable (Inciardi & Harrison, 2000) and that “zero tolerance, prohibition and abstinence are

not only unsuccessful in reducing drug taking behaviours, [but] also increase various drug-related harms” (Riley & O’Hare, 2000, p. 1). Harm reduction is commonly implemented through policies, programs and strategies that aim to improve the health and wellbeing of PWID by minimising the health, social and economic consequences associated with drug use (International Harm Reduction Association, 2010).

There is no universally accepted definition or model of harm reduction and therefore no consensus on the suite of actions and interventions required for effective harm reduction responses. What is agreed however, is that harm reduction responses need to be appropriate and accepted within PWID populations if they are to be effective (Australian Government Department of Health and Ageing, 2010b; Jürgens, 2005; World Health Organisation, 2012a, 2012b). Common to a number of international harm reduction approaches to the prevention of blood-borne viruses is access to sterile injecting equipment, opioid substitution therapy, condoms, targeted education and communication and appropriate testing, diagnosis and treatment for hepatitis C (Joint United Nations Programme on HIV/AIDS, 2011; World Health Organisation, 2012a, 2012b). Australia’s harm reduction response to hepatitis C encompasses a range of strategies and programs, including the distribution of sterile injecting equipment, peer education, access to opioid pharmacotherapies and primary care services (Australian Government Department of Health and Ageing, 2010b) but with varying, and not optimal, coverage. The following section will discuss the enabling factors within the policy environment with respect to the provision of Needle and Syringe Programs (NSPs), which form the cornerstone of Australia’s hepatitis C harm reduction response for the provision of sterile injecting equipment.

2.2.1.i Availability and coverage of clean needles and syringes

Access to sterile injecting equipment is a central commitment of all the national and international responses to hepatitis C harm reduction (Australian Government Department of Health and Ageing,

2010b; Peltzer & Ramlagan, 2011; World Health Organisation, 2012a, 2012b). At the time of writing, Australia has one of the largest NSP networks globally (Kwon et al., 2012; Kwon, Iversen, Maher, Law, & Wilson, 2009; Mathers et al., 2010; Razali et al., 2007). The first formal Australian NSP began operation in NSW in 1986 (Wodak et al., 2012) and by 2008, there were approximately 3,000 NSP services operating in Australia, distributing an estimated 30 million syringes during the past decade (Kwon et al., 2009). The state of NSW has the largest number of NSPs operating in Australia. In 2012, there were approximately 346 primary and secondary NSPs in NSW; 488 community-based pharmacies participating as equipment distribution outlets; 141 syringe vending machines and 46 internal dispensing chutes (NSW Department of Health, 2013b). However, it is important to note a wide variation in geographic coverage, where services were not comprehensively delivered and at the time of writing there was no NSP provision in prison-based settings.

The importance of NSPs in reducing the harms associated with injecting has been supported by mathematical modelling of hepatitis C transmission in Australia conducted by Kwon and colleagues (2009), who reported that the number of times each syringe was used before disposal was shown to be the most sensitive factor in determining hepatitis C transmission. This influence is also supported by epidemiological research that suggests that hepatitis C transmission is strongly influenced by how long a syringe is in circulation (Paintsil, He, Peters, Lindenbach, & Heimer, 2010; Ritter & Cameron, 2006). This suggests that the longer a syringe is in circulation (and not safely disposed of) the more likely it is to be reused or shared. Another important epidemiological influence on hepatitis C transmission is the percentage of injecting episodes that involve the sharing of injecting equipment. This factor has been shown to be most influenced by the number and characteristics of people present in the injecting episode (Kwon et al, 2009).

NSPs are identified as the single most important and cost-effective strategy for reducing harm amongst PWID in Australia (Commonwealth of Australia, 2010) and economic modelling has

indicated that public spending of AU\$245million on NSPs over nine years (2000-2009) had the ability to reduce the incidence of hepatitis C in Australia by 15–43%, or prevented 19 000–77 000 new hepatitis C cases (Kwon et al., 2012) and the majority of cost savings were found to be hepatitis C-related. The return on investment was four dollars for every dollar spent on NSPs (National Centre in HIV Epidemiology and Clinical Research, 2009). To reduce the transmission of hepatitis C in Australia, it has been argued that there is a need to increase, or even double, sterile syringe supply (Kwon et al., 2009).

2.2.1.ii Policy and law reform

Although it could be suggested that there has been a shift by policymakers globally to more actively attempt to balance law enforcement supply- and demand-side policies with harm reduction responses (Cohen, 1999; Levine, 2003; Taylor & Jelsma, 2012), the results of this shift have not been universal. The most noteworthy example of a country that has pursued such an alternative model in drug and law reform is Portugal, which in 2001 decriminalised the acquisition, possession and use of drugs for personal use (European Monitoring Centre for Drugs and Drug Addiction, 2011). The decriminalisation process was accompanied by decreases in reported drug use and significant declines in drug-related deaths, as well as in the resources expended in policing and prosecuting personal drug use crimes (Hughes & Stevens, 2012).

Another notable policy change in recent years has been the increased investment in needle and syringe programs in prison-based settings. To date these programs have been implemented in Azerbaijan, Belarus, Germany, Iran, Kyrgyzstan, Luxemburg, Moldova, Romania, Spain, Switzerland and Tajikistan (Voon & Ryan, 2011). In Spanish prison-based NSPs, which had been in operation for over a decade, the introduction of the prison-based NSP reduced the prevalence of hepatitis C from 40% to 26.1% (Ferrer-Castro et al., 2012). In Iran, a country with the highest heroin and opium addiction per capita in the world (Razzaghi, Movaghar, Green, & Khoshnood, 2006), a pilot NSP was

established in 2010 in three Iranian prisons. The results from this pilot found that the sharing and reuse of needles and syringes amongst the 341 prisoners enrolled in the pilot declined to zero (Shahbazi, Farnia, Keramati, & Alasvand, 2010). Australia has not introduced prison-based NSPs.

An area of policy reform that I will be discussing in the results and discussion chapters of this thesis is the illegality of peer distribution in Australia (see Chapter 7 & 8). Peer distribution is the distribution and receipt of sterile injecting equipment within networks of PWID. Peer distribution pre-dates formal, government responses for the provision of sterile injecting equipment. Yet this mode of distribution is not recognised or supported in any of the major international responses to hepatitis C harm reduction, including those in Australia. Over the last decade, there have been a number of calls to change the illegality of peer distribution in Australia. For example, the Australian National Council on Drugs describes the law that makes peer distribution illegal “as one particular lost opportunity with regard to increasing access to sterile injecting equipment” (Australian National Council on Drugs, 2013, p. 15); whilst the mathematical modelling study conducted by Kwon and Colleagues (2009) also identifies the need for the removal of legal impediments to allow secondary exchange (peer distribution) to occur within the networks of PWID, there has been no legislative change in New South Wales with respect to the distribution of sterile injecting equipment within the networks of PWID (ACT Human Rights Commission, 2013).

2.2.2 The economic environment

The economic environment consists of external (non-individual) factors in the broader economic context and conditions of everyday life of PWID which can be seen to influence their health, including the risk of acquiring or transmitting hepatitis C. These economic factors can include, but are not limited to, influences such as employment, income and the distribution of wealth. To highlight the importance of the economic environment to the transmission of hepatitis C, this section will review the body of literature reporting on social disadvantage as a micro-economic risk

environment and consider how this can be somewhat alleviated by the provision of low-threshold, or free, services for PWID. At the macro-economic level, this section will review the literature reporting on the need to balance investment in harm reduction programs and law enforcement.

2.2.2.i Social disadvantage

Micro-economic factors that influence risk in populations of PWID are shaped, and perpetuated, by social systems that reproduce poverty and social disadvantage. This disadvantage is influenced by low levels of employment among PWID populations (Richardson, Wood, Li, & Kerr, 2010) and compounded by the high costs associated with purchasing illegal drugs. Also linked to socio-economic disadvantage is the ability to secure adequate housing, an important micro-economic determinant that influences health and drug related harm among populations of PWID:

Housing is a crucial site in the day-to-day life of most individuals for the distribution of wealth, control over life circumstances, and access to social resources, as well as being an important factor in processes of social identity formation, and the establishment and maintenance of social relationships (Dunn, 2000, p. 352).

There is a growing literature reporting on the association between unstable housing and increased risk of blood-borne viruses (Briggs et al., 2009; Craine et al., 2008; Rhodes, Kimber, et al., 2006; Rhodes, Stoneman, et al., 2006). Importantly, those with unstable housing are reported to be more likely to share needles and syringes than those PWID with stable housing. An inability of PWID to meet their everyday financial needs is also reported to increase illegal income generating strategies (DeBeck et al., 2007; Moore, 2004; Richardson et al., 2010; Sherman & Latkin, 2002). Where PWID become involved with illegal income generating strategies, this increases their risk of interaction with police (DeBeck et al., 2007). When a person has limited income to meet their needs they are “disproportionately affected by poverty, homelessness and challenges to meeting everyday survival need” (McNeil & Small, 2014, p. 154). The above examples highlight how social disadvantage and

marginalisation intersect with micro and macro influences in varying environments and how this intersection creates “unequal social conditions that most users find themselves by product of their often lower socioeconomic background and their status outside the law” (Wodak & McLeod, 2008, p. 581).

2.2.2.ii Provision of low-threshold services

The influence of social disadvantage within the micro-economic environment is increasingly acknowledged in the research literature and this has resulted in the development of low threshold services for populations of PWID. In Australia, these low-threshold services include the provision of publicly-funded Needle and Syringe Programs, free health care and subsidised hepatitis C treatment. In addition, a Medically Supervised Injecting Centre (MSIC) in Sydney began operation in 2001 and has been shown to reduce the morbidity and mortality associated with overdose (van Beek, Kimber, Dakin, & Gilmour, 2004); positively improve drug treatment referral and uptake (Kimber, Mattick, Kaldor, & van Beek, 2008); and reduce crime in the local area (K. Freeman et al., 2005). Although the need has been identified for developing appropriate micro-economic interventions to address other disadvantage factors, such as low threshold employment opportunities for PWID (DeBeck et al., 2007; DeBeck et al., 2011; Rhodes, 2009), these opportunities have not yet been realised in Australia.

2.2.2.iii Balancing investment in harm reduction programs and law enforcement

Most countries, including Australia, have recognised the importance of balancing investment in both harm reduction programs and law enforcement. In Australia, this balance has not been achieved: the prioritisation, and bulk of funding, is directed to law enforcement and prohibition, popularly referred to by the Global Commission on Drug Policy as the ‘war on drugs’ response (Douglas, Wodak, & McDonald, 2012). In 2009/10 66% (\$1.1b) of the total spending on illicit drugs in Australia was directed to law enforcement and 2.1% to harm reduction (\$36.1m) (Ritter, McLeod, & Shanahan,

2013a). Not only has the bulk of funding in Australia been directed towards law and order approaches, there has also been a recent decrease in harm reduction funding, from 3.9% to 2.1%; as well as a significant decline in direct spending on harm reduction programs, from \$44.8 million to \$36.1 million, representing a 20% decline in spending on harm reduction in Australia (Ritter, McLeod, & Shanahan, 2013b). The prioritisation of law enforcement over harm reduction programs in Australia has occurred despite extensive evidence of the failure of prohibition in reducing supply and consumption of drugs and subsequent increases in harm for PWID (Global Commission on Drug Policy, 2011; Wodak, 2001).

This funding (mis)allocation has also occurred in an environment where there is an increasing evidence base supporting the effectiveness and cost-effectiveness of harm reduction programs in reducing the harms associated with drug use (Kwon et al., 2012; Kwon et al., 2009; National Centre in HIV Epidemiology and Clinical Research, 2009; Palmateer et al., 2010). The influence of this unequal and unbalanced prioritisation is important because:

Spending public money is the most powerful of the policy instruments that governments have available to address drug abuse, but the resource allocation policies across drug types and intervention sectors do not sufficiently demonstrate a rational, evidence-informed approach. This is because the pattern of spending fails to give precedence to the drug types that are the source of most harm to Australian society, and to the sectors for which we have strongest evidence of the effectiveness and cost-effectiveness of the available interventions (McDonald, 2011, p. 99).

The current prioritisation of law enforcement and decreasing budgets allocated to harm reduction programs has been identified by Rhodes (2009) as a macro-level economic and policy factor that will

continue to negatively influence the transmission of hepatitis C within populations of PWID in Australia and around the world.

2.2.3 The physical environment

The concept of the physical environment is intended to draw attention to the influence of drug use *settings* in the transmission and prevention of blood-borne viruses. Understanding those aspects of the physical environment that influence risk is vital because the physical environment – or ‘place’ – is reported to be a fundamental feature of human experience (Duff, 2011). The body of literature reporting on place as an important environmental influence therefore seeks to create further understandings of how the physical environment can support (place as an enabling environment), or hinder (place as a risk environment), PWID health and wellbeing. However, it is important to note that this body of literature is more commonly reported in relation to the risks and therefore place as an enabling environment has received little attention in the research literature (Duff, 2010; McNeil & Small, 2014). To highlight the importance of the physical environment to the transmission of hepatitis C, this section will review the literature reporting on policing practice, drug using places and place as an enabling environment.

2.2.3.i Policing practice

Another important environmental influence on the risks associated with illicit drug use is the fact that it is illicit. An extensive body of evidence reports on the experiences of PWID with police, policing practices and the law enforcement system, an environment that has been described as creating “a climate of fear and uncertainty” (Burris et al., 2004, p. 134). With respect to hepatitis C transmission, fear of police can discourage safe injecting practice and safe needle and syringe disposal (Aitken, Moore, Higgs, Kelsall, & Kerger, 2002); decrease the willingness of PWID to carry sterile injecting equipment (Rhodes et al., 2003; Sarang, Rhodes, Sheon, & Page, 2010; Strathdee et al., 2010); and subsequently increase high risk injection practices (Dixon & Coffin, 1999; Maher &

Dixon, 2001; Maher, Dixon, Swift, & Nguyen, 1997). Given the influence that the law and its enforcement has on the way drugs are used, the law has been regularly identified as a macro-physical level influence on hepatitis C risk (Burris et al., 2004).

2.2.3.ii Drug using places

The body of literature reporting on place as an important micro-physical level of influence most commonly reports on either prisons or public injecting; this section of the review will focus on the latter. Injecting in public places is commonly associated with unsterile environments and the need to rush due to fear of being observed, which are reported to increase the transmission of blood-borne viruses, including hepatitis C (Rhodes, Kimber, et al., 2006; Rhodes et al., 2007; Small, Rhodes, Wood, & Kerr, 2007; van Beek, 2000). The need to inject in public also intersects with the macro-physical environment (increasing the chance of coming to the attention of police) and with the micro-economic environment (associated with unstable living conditions and homelessness) (Harris & Rhodes, 2013a; C. Kim et al., 2009; C. Miller et al., 2002; Stein & Nyamathi, 2004).

The literature reporting on place as an important risk environment has also highlighted how the geographical location of PWID services can influence the health and wellbeing of populations of PWID. The provision of services for PWID and the location of these services intersects with community attitudes (macro-social level factors), which may not always be supportive of PWID-based services because “spatial stigma can extend beyond the individual in the location of services used and frequented by clients” (Tempalski & McQuie, 2009, p. 8). Smith (2010) reported on a methadone clinic that was rejected as unsuitable by local residents. Smith reports that the negative responses by the neighbourhood residents ultimately influenced the clients’ willingness to access the service. Disruptions in access to health care and other support services, can increase risk behaviours associated with infectious disease transmission and overdose (Kerr, Small, & Wood, 2005).

2.2.3.iii Place as enabling

The role of place as an enabling environment regarding the prevention of harms associated with injecting drug use is relatively unexplored in the research literature, however, in a study conducted by Duff (2009), place, particularly urban settings, was described as a physical environment that can act to increase a sense of belonging and connectedness. In a later article, Duff (2010) further explored the relationship between people and resources in specific social settings and argued that places can become enabling environments “to the extent that they facilitate the production and circulation of those resources necessary for the realisation of specific enabling practices and process” (Duff, 2010, p. 338). These resources are noted to include material and economic resources; such as employment, welfare payments, low-threshold services, and informal benefits like bartering and exchange as well as social resources, such as “the carried processes and relationships that support the creation and maintenance of personal networks” (Duff, 2010, p. 339). Duff consistently notes that the ability of PWID to build social ties and enhance local social networks is directly influenced by the particular urban setting in which PWID are located and “the extent to which specific settings exhibit risk and/or enabling processes will thus depend both on the behaviour of individuals and groups, as well as the diverse material and structural properties of such places” (Duff, 2011, p. 150). Importantly, Duff concludes that it is through the mobilisation of different people and the resources between them that can create, or disrupt, cultures of care.

2.2.4 The social environment

The social environment, in Rhodes’ conceptualisation of the risk environment framework, focuses on people’s relationships, particularly those micro-social and peer group norms that are believed to be important factors that influence risk (Rhodes, 2002, 2009). Understanding social norms requires an appreciation of social relationships, particularly since the “attitudes and values held by members of one’s social reference group provide information about actions that are likely to be reinforced, supported, and accepted within that social network” (Amirkhanian, Kelly, Kabakchieva, McAuliffe, &

Vassileva, 2003, p. 59). Attitudes, values and social norms can therefore play an important role in how people behave and can act as significant barriers to altering behaviours that may increase risk, as well as supporting behaviour change and practices that may reduce risk (Latkin, Forman, Knowlton, & Sherman, 2003).

The body of literature reporting on the influence of relationships with peers and intimates is not limited to the network literature and these studies consistently report that “[the individual’s] perceived risks, peer influences, and type of injection partner” (Bailey et al., 2007, p. S18) are important predictors of syringe sharing and subsequent hepatitis C transmission. Also emphasised in this literature is evidence that the prevention of hepatitis C is particularly suitable and amenable to peer-based intervention (Bailey et al., 2007; Garfein et al., 2007; McNeil & Small, 2014; Newland & Treloar, 2013; Treloar & Abelson, 2005). However, understanding social network factors that influence hepatitis C transmission risk beyond the interpretation of individual accounts, such as those reported in the body of literature reporting on the influence of peers, requires the collection and analysis of relational data, and therefore different research designs and methods. Therefore, the focus on relationships in this study extends the existing literature by showing what is missed by not attending to the influence of relationships in the context of communication, risk and practice.

One approach that has been increasingly employed to collect, manage and analyse relational data is social network analysis. The aim of social network analysis is typically to examine the influence and effect of social context and network structure on health risks, and to consider how micro-social contexts and network structure influence individual behaviour and the spread of epidemics such as HIV and hepatitis C (Lovell, 2002). As identified in the thesis introduction, research reporting on hepatitis C transmission risk that moves beyond the individual as the unit of analysis in the micro-social environment remains limited, which has implications for generating deeper understandings of

the different micro-social contexts that can influence hepatitis C transmission risk and prevention (Lovell, 2002).

To highlight the importance of the social environment to the transmission of hepatitis C, this section will review a diverse body of literature reporting on the macro-social environment, including stigma and marginalisation and mass media hepatitis C campaigns. This section will then review the body of evidence reporting on the influence of the social network in hepatitis C transmission and prevention, to build a case for how a qualitative social network research approach can generate nuanced and contextually specific understandings of the social network as a specific site of influence in prevention in the social networks of PWID.

2.2.4.i Stigma and marginalisation

Hepatitis C-related stigma and discrimination operate as crucial macro-social level influences in the prevention of hepatitis C. In fact, hepatitis C-related stigma has been described as an essential consideration in any assessment of hepatitis C (Fraser & Treloar, 2006; Paterson, Backmund, Hirsch, & Yim, 2007; Treloar, Rance, & Backmund, 2013). Stigma is believed to be shaped by an interplay between interpersonal, institutional and structural forces (Rhodes et al., 2012). The literature clearly indicates that hepatitis C-related stigma can affect a person's sense of well-being, including high levels of anxiety, depression, and an increased (and sometimes exaggerated) fear of transmission (Grundy & Beeching, 2003; Janke, McGraw, Garcia-Tsao, & Fraenkel, 2008; Sgorbini, O'Brien, & Jackson, 2009). Stigma is also known to discourage people from seeking health care (Ahern, Stuber, & Galea, 2007; Anti-Discrimination Board of NSW, 2001; E. Miller, McNally, Wallace, & Schlichthorst, 2012; Treloar et al., 2013), which would directly impact on the prevention, treatment and care of hepatitis C.

Before reviewing the available literature on hepatitis C-related stigma, it is important to note that an extensive body of literature has described the ways in which stigma is conceptualised and understood. However, within this literature there is also a considerable lack of agreement about what stigma is and how to conceptualise it. Further, the literature is characterised by a focus on the individual which is commonly identified as a limitation in research that aims to understand stigma as a concept, and an influence of stigma on hepatitis C risk and prevention (Link & Phelan, 2006; Parker & Aggleton, 2003; Paterson et al., 2007). Within the hepatitis C literature, stigma is most commonly reported with reference to Goffman's theorisation of stigma as a spoiled identity, where stigma is described as the labelling or stereotyping of an "attribute, behaviour, or reputation which is socially discrediting" (Goffman, 1963). Other authors identify power as the central component of stigma, which can result in a process of "labelling, stereotyping, separation, status loss and discrimination" (Link & Phelan, 2006, p. 363).

In Australia, stigma against people with hepatitis C, including populations of PWID, has been described as 'rife' (Anti-Discrimination Board of NSW, 2001) and instances of hepatitis C-related stigma have been widely reported in a variety of contexts, such as health care and legal settings, from family, friends, employers, insurance providers and/or society as a whole (Butt, 2008). Across these distinctive settings and roles, there is a widely acknowledged association, and sometimes indistinguishable relationship, between the stigmatisation of hepatitis C and that of injecting drug use (Day, Ross, & Dolan, 2003; Hopwood, Treloar, & Bryant, 2006; Paterson et al., 2007; Simmonds & Coomber, 2009). The body of literature reporting on hepatitis C-related stigma has tended to focus, almost exclusively, on hepatitis C-related stigma in health-care settings. As health-care settings can enhance, or necessitate, the likelihood of disclosing a hepatitis C infection (Harris & Rhodes, 2013a), this may at least partially explain why instances of hepatitis C-related stigma are more commonly reported in this setting. The enactment of hepatitis C-related stigma in these settings typically labels people as personally responsible for their exposure to hepatitis C (Habib &

Adorjany, 2003; Hopwood & Treloar, 2006; Hopwood et al., 2006; Simmonds & Coomber, 2009); and therefore people living with hepatitis C can be subjected to inappropriate use of infection precautions or controls (Butt, 2008; Day, Jayasuriya, & Stone, 2004; Hopwood & Treloar, 2006; Treloar & Hopwood, 2004); to receive a lesser or inappropriate level of care (Ahern et al., 2007); or be excluded from accessing services (Anti-Discrimination Board of NSW, 2001; Brener, Von Hippel, & Kippax, 2007; Day et al., 2004; Day et al., 2003; Simmonds & Coomber, 2009).

Within this body of literature, the disclosure of hepatitis C, whether intentional or not, can be seen to influence how hepatitis C-related stigma is both felt and enacted. As it is not uncommon to receive a negative response (Hopwood Nakamura, et al 2010), or even a “hysterical response” (Crofts & Louie, 1997, p. 90), to a disclosure of hepatitis C infection, “most people with hepatitis C speak of learning very soon after receiving their diagnosis to be discrete or secretive about disclosing to prevent stigma” (Butt, 2008; 719). In this environment, decisions regarding hepatitis C disclosure become strategic and nuanced (Rhodes & Treloar, 2008) and it has been suggested that disclosure outside of immediate friendship networks and trusted others may not be common (Fraser & Treloar, 2006; Habib & Adorjany, 2003; Harris, 2005; Hopwood, Nakamura, & Treloar, 2010; Hopwood & Treloar, 2003; Sutton & Treloar, 2007).

The ways in which hepatitis C stigma is enacted within networks of PWID has been reported in only a few studies and these typically draw on Goffman’s definition of stigma as a negative label, believed to create a ‘spoiled identity’ for those living with hepatitis C. For example, a study conducted with young PWID in a regional Australian setting suggested that the young people who took part believed that others who were hepatitis C positive didn’t care about themselves or others, held weaker morals and were irresponsible (Fitzgerald, McDonald, & Klugman, 2004). In another study of hepatitis C-related stigma within networks of PWID, negative stereotyping of people with hepatitis C was also reported as well as the belief that people with hepatitis C were more likely to participate in

riskier injecting practice (Simmonds & Coomber, 2009). However, these studies did not report on the particular social network dynamics surrounding hepatitis C infection disclosure within networks of PWID, and therefore it is unclear how disclosure of status occurred or whether those who were hepatitis C positive were aware of, and subsequently feared, these negative judgements.

2.2.4.ii Mass media and awareness campaigns

Although this thesis has focused on populations of PWID, it must also be acknowledged that there is relatively limited awareness of hepatitis C among the general Australian community. For example, limited hepatitis C knowledge has been reported in studies among secondary school students (Lindsay, Smith, & Rosenthal, 1999; Smith et al., 2006), young people at risk of acquiring hepatitis C (Bryant, Ellard, Fisher, & Treloar, 2012), and Australian university students (Hopwood, Brener, & Wilson, 2012). At the time of writing, there has only been one large scale public health awareness campaign undertaken in Australia to date, which was a mass media campaign conducted in 2001 that delivered hepatitis C-related information to the wider Australian community through print, radio and television mediums (Smith et al., 2006). Whilst the authors of this study note that this campaign did increase awareness of hepatitis C, they also noted that “there is room for further improvements in community understanding about hepatitis C” (Smith et al., 2006, p. 492). Mass media campaigns, especially those that have the ability to reduce hepatitis C-related stigma, have a potentially valuable role to play in this endeavour (Smith et al., 2006).

2.2.5 Understanding the role of the social network in hepatitis C transmission

2.2.5.i Social network membership and transmission risk

Within the HIV and hepatitis C research fields the most common approach to exploring the micro-social risk environment has been through a mapping of the transfer of blood-borne viruses within specific social network relationships, as part of large-scale epidemiological social network studies.

Where transmission clusters are found to occur, these studies have subsequently explored how specific injecting or sexual relationships might have influenced the transmission of HIV and hepatitis C in these specific network settings.

Social network analyses conducted in the HIV research field have commonly investigated the character and dynamics of relationships that occur within social networks. A main aim of these analyses is to understand how membership (specifically the socio-demographic characteristics of individual members) and composition (network structure) of particular social networks operate as micro-social influences in the transmission of blood-borne viruses. Within this literature, the transmission of hepatitis C within the networks of PWID is commonly reported with respect to the socio-demographic characteristics of network members, particularly gender (Bourgois, Prince, & Moss, 2004; Davey-Rothwell & Latkin, 2007; Miller & Neaigus, 2001; Neaigus et al., 1994), ethnicity (Adimora & Schoenbach, 2005; Friedman, Curtis, Neaigus, Jose, & Des Jarlais, 1999; Weeks, Clair, Borgatti, Radda, & Schensul, 2002), and age (Amirkhanian et al., 2003; Tyler, 2008; Unger et al., 2006). These studies suggest that the socio-demographic characteristics of network members create inequalities in power relations within social networks and through this, network members, and sometimes whole networks, face increased, or decreased, risk of exposure to HIV.

With respect to network structure, size of the network has also been shown to be implicated in HIV transmission, with larger networks showing greater rates of equipment reuse (De, Cox, Boivin, Platt, & Jolly, 2007; Latkin et al., 1995; Mandell, Kim, Latkin, & Suh, 1999). Being a member of a large social network has also been found to decrease the control an individual has in the injecting episode, to increase the number of unplanned injecting episodes or to increase situations where PWID have mistakenly used other people's injecting equipment (Wodak & Crofts, 1996). Large social network size and instability in social network relationships have also been found to be associated with syringe sharing and HIV transmission risk (Cepeda et al., 2011). Instability of network relations is commonly

reported with respect to conflict (Tyler, 2008) and network turnover (Costenbader, Astone, & Latkin, 2006; Hoffmann, Su, & Pach, 1997; Neaigus et al., 1995), both of which have been implicated in HIV transmission risk.

Social network studies have not been commonly undertaken in relation to hepatitis C and those that have been reported in the literature have tended to focus on the influence of social relationships on the spread of hepatitis C viral markers; similar to the large-scale, epidemiological HIV studies discussed previously. Within these studies, the primary aim was to measure the overlap of relationships between individual PWID and their injecting networks, to understand if patterns of hepatitis C virus infection were similar. For example, transmission clusters have been found to be correlated with injecting relationships located in specific geographic sites (Sacks-Davis, Daraganova, et al., 2012). Like those studies conducted in the HIV research field, these hepatitis C-focused studies have typically concentrated on identifying particular socio-demographic characteristics of network members and their associated transmission risk. For example, Vietnamese-Australian PWID, living in Melbourne, were found to often reside in similar areas and to therefore be more likely to inject with people of their own cultural background, which is reported to directly influencing hepatitis C transmission within this migrant community (Aitken et al., 2008). The age of social network members has also been shown to influence risk of exposure to hepatitis C and the distribution of hepatitis C genotype sub-types in Sao Paulo, Brazil (Romano et al., 2010). Common to the findings of the small number of hepatitis C-related social network studies is the suggestion that social network factors were a, if not the, key influence of the rate and pattern of hepatitis C transmission (Romano et al., 2010). However, more complex and nuanced social dynamics associated with hepatitis C risk, such as peer group norms, were not typically investigated in these studies.

The influence of network membership and hepatitis C transmission risk was also reported in another large-scale, quantitative social network analysis, conducted in Australia by Aitken and colleagues

(2009). In this study, having at least one person who was hepatitis C negative in an injecting network was found to be associated with a reduction in the risk of other individuals within the network being exposed to hepatitis C (Aitken, Lewis, Hocking, Bowden, & Hellard, 2009). As a result of this finding, the researchers suggested that knowledge of network members' hepatitis C status could enable an individual to exert greater control over network selection and composition, therefore lowering their risk of acquiring hepatitis C by only participating in injecting networks based on what they believed was the negative status of network members. Whilst understanding the benefits of having a person with a negative hepatitis C status in a network is interesting, this assumption requires further thought. For example, the assumption that network members would, or could, disclose their hepatitis C status does not acknowledge the extensive research that highlights how social pressures, such as stigma and discrimination, strongly influence, and in a number of cases preclude, the disclosure of hepatitis C infection (see macro-social risk environment earlier in this section). This reveals a particular need to understand how disclosure dynamics are enacted and negotiated in networks of PWID, if disclosure is to be promoted as a harm reduction strategy.

2.2.5.ii Social dynamics in the sharing and reusing of injecting equipment

The literature reporting on the influence of the micro-social environment in the prevention and transmission of blood-borne viruses has increasingly focused on intimate, sexual relationships, i.e. couples, as an important micro-social 'setting', or social network relationships that have the potential to either positively or negatively influence the transmission of blood-borne viruses.

Within the HIV research field, research suggests that sharing and reuse of injecting equipment is complex and influenced by a number of structural, compositional and behavioural factors and is seen to be more acceptable within close relationships of PWID (De, Cox, Boivin, Platt, & Jolly, 2008; Klee, Faugier, Hayes, Boulton, & Morris, 1990; Rhodes et al., 2005). Importantly, the control that an

individual can exert in injecting episodes and the roles and quality of relationships between sexual partners have been reported to influence injecting practice and drug use patterns (De et al., 2007; Grund et al., 1996; Neaigus et al., 1996). Issues of control have also been shown to be influenced by micro-economic factors and an individual's ability to access finances, drug markets and sterile injecting equipment (Hahn et al., 2002). When an individual is dependent on their partner for drugs or injecting equipment, the literature suggests they "may feel limited control over their behaviour and cannot easily modify their risky practices" (Davey-Rothwell & Latkin, 2007, p. 700). Furthermore, if individual PWID do not have access to finances, drug markets or injecting equipment, the ability to challenge or discuss practices that may increase transmission risk with their partner may be restricted due to a fear that access to drugs or equipment may be compromised.

Within the hepatitis C research literature, it is also suggested that the sharing of injecting equipment within sexual relationships is complex and rather than being viewed as random or arbitrary (Bryant, Brener, Hull, & Treloar, 2010), sharing practices are more appropriately described as deliberate or considered (Harris & Rhodes, 2013b). This deliberate sharing is believed to be influenced predominantly by issues of intimacy and trust (Bryant et al., 2010; Fraser, 2013; Fraser, Treloar, Bryant, & Rhodes, 2013; Jackson et al., 2002; Jackson, Parker, Dykeman, Gahagan, & Karabanow, 2010; Rhodes & Quirk, 1998; Rhodes & Treloar, 2008). Little, or no, evidence of discussion of hepatitis C infection has been reported to occur within sexual relationships (Bourgois et al., 2004; Bryant et al., 2010; Fraser, 2013; Rhodes & Quirk, 1998; Rhodes & Treloar, 2008; Seear et al., 2012) and therefore the evidence regarding the influence of disclosing hepatitis C sero-status and the influence that this disclosure has on injecting practice within sexual relationships is unclear' (Bryant et al., 2010). Furthermore, issues of 'risk equivalence', in which a number of sexual and injecting practices are believed to constitute the same risk for hepatitis C transmission, has also been explored with respect to the sharing of injecting equipment in couples. For example, those couples who do not use condoms have also reported sharing of injecting equipment, believing this form of

sharing with their partner posed no additional risk (Fraser, 2013; Harris & Rhodes, 2013b; Jackson et al., 2010; Seear et al., 2012).

When research focuses on couples as a site of risk in relation to hepatitis C, there has also been a tendency to concentrate on the gendered dimensions of the sharing and reuse of injecting equipment, particularly since control of drugs, equipment and other resources has been shown to typically be controlled by the male partner, at least in heterosexual relationships (Bourgois et al., 2004; Lazuardi et al., 2012). For example, a study by Bourgois and colleagues (2004) found that young, homeless female PWID often formed relationships with typically older men, for reasons of intimacy, love and protection. Within these relationships, which could also be accompanied by sexual predation, financial domination and social isolation, young women were found to be at greater risk of acquiring blood-borne viruses, including hepatitis C, because those particular relationship dynamics reduced control or the ability to challenge circumstance or specific events, including those occurring within an injecting episode.

A number of research studies have now proposed new recommendations regarding the facilitation of micro-social environments that reduce the intended and unintended sharing of injecting equipment in couples. For example, the re-design of the packaging and colours of needles and syringes has been identified as a micro-social environment innovation that could influence the sharing of injecting equipment within sexual relations. In a UK-based study the authors suggest that if needles and syringes were made in different colours, it would permit easier identification of who each syringe belonged to within a couple (Harris & Rhodes, 2013b), and in an Australian study it was suggested re-designing the packs that needles and syringes come in so that they can be split into two and incorporate couples-based harm reduction messages (Fraser, 2013). Additionally, Bryant and colleagues (2010) have also argued that couples-based interventions could be better considered in approaches to hepatitis C testing, and could “include pre and post counselling and skills

development for negotiating sero-status and needle sharing ... (and) treatment services could be offered simultaneously to both partners so that couples can reduce or stop their drug use together” (Bryant et al., 2010, p. 186). However, the recommendations from these studies have (to date) not been included in the development of new interventions.

The conscious sharing and reuse of injecting equipment has also been observed in relationships between close friends. For example, Bourgois (1998) employed an ethnographic study design to explore risk and vulnerability among homeless men who inject drugs and were living in a temporary camp on the edges of San Francisco. Although focused on HIV, the findings highlighted how the sharing of injecting equipment was influenced by a variety of economic, emotional, biological and social imperatives. Social network factors were identified as ‘a central organising dynamic’ that shaped HIV transmission risk because social relationships were seen to help in avoiding withdrawal and overdose and to minimise risk of arrest. In making sense of these relationships, Bourgois introduced the concept of the ‘moral economy’: which he defined as the “pragmatics of income-generating strategies and the social symbolic hierarchies of respect, identity and mutual dependence (that) shape risk” (Bourgois, 1998, p. 2323). The notion of the moral economy directs attention to social network relationships, hierarchies, rules and norms, as a way of broadening understandings of the influence that social network relations can have on equipment sharing and reuse, which in a number of cases could be seen to be in conflict with the public health imperative to ‘not share or reuse needles and syringes’. Within these moral economies, injection practices that may increase harm have also been shown to be influenced by an individual’s lack of resources to procure drugs (Lovell, 2002). This lack of financial resources is believed to influence the need to have, or form, relationships, and to combine resources. Where financial inequities exist between people who have combined resources, these inequalities can influence the choices that different individuals have available to them in specific injecting episodes. This notion of the moral economy also has particular

resonance regarding the network influences examined in this study, and therefore these will be discussed in the network results chapters where appropriate.

2.2.5.iii Social networks as enabling

The influence of the social network in developing and maintaining social network norms that create enabling environments has been explored in a number of HIV social network studies. For example, HIV-related social network studies have often argued that interventions that target the social network make the most efficient use of prevention resources because these interventions target social norms linked to HIV risk (Amirkhanian et al., 2003; Amirkhanian, Kelly, & McAuliffe, 2005; Broadhead et al., 1998; Friedman et al., 2007; Heckathorn, Broadhead, Anthony, & Weakliem, 1999; Latkin & Knowlton, 2005; Latkin, Kuramoto, Davey-Rothwell, & Tobin, 2010; Latkin, Sherman, & Knowlton, 2003). Within this literature, the action for change is occurring within the community at risk rather than being directed by organisations or outsiders. Therefore, social networks are believed to mobilise action (Carruthers, 2007), positively influence “cultures of support for risk reduction and risk avoidance” (Friedman et al., 2007, p. 251) and create enabling environments to prevent disease transmission and drug related harm (Duff, 2009). It has also been suggested that if influential individuals can be identified within specific social network structures, they may be able to advise and influence other network members regarding HIV risk reduction. For example, in a study conducted by Friedman and colleagues (2007), social networks were shown to mobilise in response to the threat of HIV and developed collective responses known as an ‘intravention’.

There have been no studies that have explored the influence of social networks on hepatitis C-related social norms, although a number of studies have reported the importance of acknowledging that risk as a social construction (Douglas, 2013; Mayock, 2005) because risk perceptions are influenced and shaped by a variety of social, cultural, political and economic contexts (Mayock, 2002, 2005; Moore, 2004; Rhodes, 2002, 2009; Rhodes & Treloar, 2008). When socially constructed

perceptions of risk are acknowledged, situational, relational and environmental influences become crucial and cannot be over-emphasised (Alaszewski, 2005). In addition, a number of studies have reported on how hepatitis C may become accommodated into the everyday lives of PWID (Davis & Rhodes, 2004; Wozniak, Prakash, Taylor, & Wild, 2007). The attitudes surrounding this normalisation are in part dependent on the membership, relationships and social network dynamics of specific networks of PWID (Roy, Nonn, Haley, & Cox, 2007; Wozniak et al., 2007). However, as this body of evidence has used the individual as the unit of analysis, and the specifics related to social network dynamics have not been assessed, the influence of these particular factors relating to social networks in developing and shaping knowledge beliefs about hepatitis C has not been examined in any detail.

Although there is a gap in the literature exploring the influence of social network relationships in creating enabling environments and understanding their effect on hepatitis C transmission, this is not to say that protective and enabling responses to hepatitis C transmission do not occur within the networks of PWID. A number of non-network studies report evidence of hepatitis C harm reduction occurring within the social relationships of PWID. For example, the distribution of sterile injecting equipment within networks of PWID (see peer-distribution reported later in this section) appears to be a common response to injecting-related harm, including hepatitis C (Benyo, 2006; Bryant & Hopwood, 2009; De et al., 2008; Hahn, Evans, Davidson, Lum, & Page, 2010; Lenton, Bevan, & Lamond, 2006; Murphy, Kelley, & Lune, 2004), within networks of PWID. Jackson and colleagues (2010) report that social network relationships among PWID were formed as a protective mechanism, facilitating access to assistance (especially in an emergency) from known and trusted others. In addition, Southgate and Hopwood (2001) described harm reduction and prevention strategies employed by gay men who use drugs, identifying a “network nanny role”, that could be seen to target prevention at the network level. The authors stress the importance of recognising “lay

experts in reducing drug related harm” (Southgate & Hopwood, 2001, p. 331), seen to be particularly crucial because:

Personal experiences of drug use, teaching others about safe modes of administration and demonstrating safe and controlled drug use through their actions; they provided a wealth of knowledge about types of drugs and their combined effects, the sequencing and dosing of drugs and advice on which drugs were suited to particular sexual and social activities (Southgate & Hopwood, 2001, p. 330).

Although there is increasing evidence of the influence that social networks can have on the transmission (and prevention) of hepatitis C among PWID populations, to date formal prevention efforts have continued to focus, almost exclusively, on the individual. For example, in a study exploring the content of 218 hepatitis C education print materials in Australia, 74% of all materials only addressed the individual and although 14% of materials addressed specific groups of PWID, such as women, indigenous and prison-based injecting, only two materials specifically addressed injecting practice in social contexts (Dwyer, Fraser, & Treloar, 2011). Numerous critiques of the individualistic focus of hepatitis C-related health promotion for PWID have been voiced in the academic literature (Bryant et al., 2010; Dwyer et al., 2011; Fraser, 2004; Treloar et al., 2008), and have concluded with calls for deeper and more exploratory understandings of social relationships as a specific site of influence in prevention and transmission of hepatitis C (Fraser, 2013; Fraser et al., 2013; Jackson et al., 2010; Rhodes, 2009; Rhodes & Treloar, 2008). However, these calls are not currently reflected, or incorporated in, current harm reduction and service provision efforts. This may be influenced by limited funding allocated to harm reduction efforts (see the sections on economic and policy environments), particularly when understanding and supporting social network-based harm reduction may be more complex and resource intensive than efforts that only address individual PWID, and will also require new modes of management and working culture

within harm reduction services. By failing to acknowledge or respond to the range of social, economic and structural factors that can influence the lives of PWID, of which injecting practice is likely to only be one, individually-focused prevention efforts may inadvertently increase the risk that the prevention effort is intending to address (Bourgois, 1998; Bourgois et al., 2004; Dwyer et al., 2011; Fraser, 2013).

2.2.5.iv Informal peer-based communication

Informal peer-based communication is a social network level influence that is reported to be an “integral aspect of many drug user networks and that the drug user grapevine is an important conduit of information and intelligence”(Power, Jones, Kearns, & Ward, 1995, p. 103). From an individual perspective, the research suggests that the main challenge within networks of PWID is not to encourage informal communication, as this already takes place. Rather, the literature suggests that there a need to ensure that hepatitis C is prioritised and discussed among social networks (Rhodes & Treloar, 2008), whilst ensuring that the information and knowledge that is being exchanged within the networks of PWID is informed and evidence-based (Madden & Cavalieri, 2007; Treloar & Abelson, 2005).

Network-based studies highlight how communication within the social networks of PWID can facilitate both risk and enabling environments regarding hepatitis C. For example, Wagner and colleagues (2013) report on the positive influence of informal communication occurring within social networks of PWID with respect to prevention and participation in overdose training. The authors of this study found that social norms influence (and increase) the value placed on overdose training (Naloxone) within PWID social networks: when at least one network member was trained in overdose assistance, this encouraged others to be trained and for there to be “active communication within the networks about overdose-related deaths” (Wagner et al., 2013). Conversely, in another study that explored the social acceptability of discussing HIV risk and condom

use, the researchers reported that these topics were not viewed as acceptable subjects of discussion within the study's networks. Importantly, it was the perception that these topics were 'taboo' that was key here, with a lack of discussion believed to be exacerbated by a fear that other social network members would find talking about these topics unacceptable or result in rejection or exclusion from the network (Latkin, Forman, et al., 2003).

An increasing body of literature has also explored the disclosure norms of blood-borne virus infection among social network groups. The literature suggests that disclosure of hepatitis C infection within networks of PWID is inconsistent. Some studies suggest that there are strong hepatitis C disclosure norms evident in the networks of Hungarian PWID and no hepatitis C-related stigma was found (Gyarmathy, Neaigus, Ujhelyi, Szabó, & Rácz, 2006). Strong hepatitis C disclosure norms were also assumed in a study conducted in Seattle by Burt and colleagues (2009), where 53% of participants who shared injecting equipment with others also reported knowing the hepatitis C antibody status of the person they shared equipment with. As a result, the authors suggest that hepatitis C sero-sorting (the practice of consciously selecting injecting partners and equipment based on known hepatitis C status) was occurring and should be considered as an example of an informal hepatitis C prevention practice.

Conversely, there is also a body of evidence from the US which suggest that there are significant barriers to disclosing a hepatitis C infection to other PWID and sex partners. Although the epidemiological literature reports a correlation between awareness of hepatitis C status and choice of injecting partners (Smith et al., 2013), other social research has highlighted that hepatitis C disclosure is a more nuanced social interaction, which is also influenced by macro-social issues, such as stigma (reported earlier in this chapter). For example, in a study of young PWID (under 30 years of age) conducted in San Francisco, 49% of study participants were shown to be unaware of their injecting partners and friends' hepatitis C status (Hahn et al., 2010). In a study by Owens (2013), the

social forces underlying barriers to disclosing a hepatitis C infection within the sexual relationships of men who have sex with men were examined. Although this study was not focused on injecting practices, it has highlighted how disclosing a hepatitis C infection in these specific social network settings was believed to create real, or perceived, fears of sexual rejection. These fears were believed to cause shame and further fear, silencing the disclosure of hepatitis C infection (Owen, 2013).

The relationship between disclosure and injecting behaviour has also been explored. For example, in a study conducted by Hahn and colleagues (2010) discussed previously, young PWID in San Francisco who did not know their partners hepatitis C status were as likely as those who did to share the injecting equipment of their partner (Hahn et al., 2010). This finding was replicated in another cohort of young PWID in San Francisco, where no change in drug use and equipment sharing was found after being diagnosed with hepatitis C (Tsui et al., 2009). In a Scottish study conducted by Palmateer and colleagues (2008), the authors report no significant differences between the sharing of injecting equipment between those who reported having a previous test for hepatitis C, compared to those who had not. This finding was also reported in an Australian network study, where no change in injecting risk, such as reusing or sharing other PWID injecting equipment, was reported following a positive test for hepatitis C (Aspinall et al., 2014). These findings “did not provide evidence of a benefit of testing per se but did lend some support to the theory that HCV status perception affects injecting risk behaviour” (Palmateer et al., 2008, p. 383).

The literature reporting on the nature of hepatitis C-related communication occurring within populations of PWID has also identified that (at least in some contexts) the delivery of hepatitis C – related communication in peer-based education programs still faced significant barriers. For example, a hepatitis C peer education program in NSW revealed a level of reluctance among some regarding discussing hepatitis C with their peers and therefore, in this program, messages were

shown to be more likely to be delivered with respect to safer injecting rather than hepatitis C more specifically (Newland & Treloar, 2013). The use of safer injecting messages was viewed as acceptable and relevant information, while hepatitis C-related information was not. Hepatitis C-related stigma was also identified as an important influence in the delivery of hepatitis C information in a Scottish peer education program, where some people felt uncomfortable raising hepatitis C with others they did not know well (Anderson, McConville, & Neale, 2013).

Hepatitis C-related disclosure norms have also been explored with respect to wider community disclosure. For example, in an Australian study of PWID recruited from the Hepatitis C Council and an inner-Sydney NSP, 75% of participants reported disclosing a hepatitis C infection to a regular partner and family and 69% had disclosed to friends. Hepatitis C disclosure in this study was believed to be associated with the number of people a person knew who were also living with hepatitis C, their level of education and those people experiencing hepatitis C symptoms (Hopwood et al., 2010). Although this study suggests a clear pattern of norms regarding hepatitis C disclosure in social networks, PWID who utilise services such as the Hepatitis C Council and NSP were shown to be more likely to be engaged with services, which may not be comparable to other PWID, especially those not engaged with services.

2.2.5.v Peer distribution (secondary exchange)

As previously identified in the policy section of this chapter, peer distribution involves PWID accessing sterile injecting equipment from authorised services and then passing this equipment onto their friends and acquaintances. This mode of distribution of sterile injecting equipment is not formally acknowledged or promoted by publicly-funded NSPS in Australia due to its illegality. Peer distribution could be seen to facilitate a micro-social enabling environment because it provides alternate access points to sterile injecting equipment. Peer distribution has been described in the research literature as an informal, community-driven practice, based on pre-existing relationships.

These relationships are believed to provide 'natural' opportunities for sterile injecting equipment distribution to occur (Snead et al., 2003). By locating the distribution of equipment in the social relationships among PWID, peer distribution is believed to reach larger peer networks and geographic areas than existing models of equipment distribution, such as NSPs (Broadhead et al., 1998) and populations of PWID that traditional services cannot always reach, such as women and young people (Anderson, Clancy, Flynn, Kral, & Bluthenthal, 2003; Broadhead et al., 1998; Stopka, 2006; Voytek, Sherman, & Junge, 2003). The cost-effectiveness of peer distribution has been widely acknowledged (Anderson et al., 2003; Bryant & Hopwood, 2009; Irwin, Karchevsky, Heimer, & Badrieva, 2006; Lorvick et al., 2006; Tyndall et al., 2002), as this form of distribution is voluntary and therefore involves no added costs to a service.

Peer distribution is currently prohibited in Australia as only authorised services, and the nominated people within these services, are legally permitted to distribute sterile injecting equipment (NSW Government, 1985). However, this illegality appears to have had little impact on the willingness of PWID to facilitate access to sterile injecting equipment among their friendship networks. For example, the onward supply of needles and syringes was reported by one in three participants in the Australian Needle and Syringe Program Survey (National Centre in HIV Epidemiology and Clinical Research, 2010) and one in two study participants in a South-East Sydney pharmacy-based study (Bryant & Hopwood, 2009). The study by Bryant and Hopwood (2009) also reported that 21.7% of all equipment received was distributed by PWID within their social networks, most commonly to friends (51.6%) and partners (27.4%). Peer distribution as a common and informal practice is extensively reported in the international literature, particularly in research conducted in the USA and Canada, and although these studies may not necessarily translate easily to the Australian context, it is useful to recognise that the distribution of sterile injecting equipment was reported by 28-75% of NSP clients in a variety of locations in those settings (Huo, Bailey, Hershow, & Ouellet, 2005; Kuyper et al., 2006; Jennifer Lorvick et al., 2006; Murphy et al., 2004; Valente, Foreman, Junge, & Vlahov, 1998;

Wood et al., 2003). Most importantly, the distribution of sterile injecting equipment reported in these studies was believed to have reached those people most at risk (Wood et al., 2003) and occurred regardless of the type of NSP program, service level distribution policy or whether peer distribution was illegal (Lorvick et al., 2006).

The literature also highlights how the practice of distributing sterile injecting equipment within networks of PWID has been accompanied by informal communication that could be seen to contribute to the prevention of hepatitis C transmission. Findings from a recent Australian study suggest that people who participated in peer distribution “were significantly more likely to tell others about some specific pieces of information, including where to get ancillary injecting equipment, where to get tested for hepatitis C, and how to get treatment for drug use” (Fisher, Wilson, & Bryant, 2013, p. 1). This finding was supported in the international literature, where it was reported that PWID often keep extra injecting equipment for those who may need them as well as educating other PWID “on the risks associated with injecting and techniques for using more safely” (Jackson et al., 2010, p. 195).

2.3 Concluding remarks

This chapter has demonstrated how hepatitis C research has expanded from investigating hepatitis C transmission risk at the level of the individual, to understanding more clearly how hepatitis C transmission risk and prevention is influenced by a range of risk and enabling factors. The risk environment framework has been influential in expanding and deepening understandings of hepatitis C transmission risks, specifically those influences at the micro- and macro- level influences, which are shaped and influenced by a diverse array of physical, social, economic and policy environments. Although this framework makes it very clear how individual and social factors relate to and shape each other, most research continues to focus on the individual as the unit of analysis. Therefore, the social network factors that operate to positively or negatively influence the

transmission of hepatitis C (within the micro-social environment) have remained largely unacknowledged and relatively unexplored, particularly through qualitative social network analysis. Social networks of people who inject drugs are reported to be important in shaping the norms that operate in relation to the sharing and reuse of injecting equipment and the strategies made available to network members to protect themselves and others against blood-borne virus transmission (S. R. Friedman et al., 2004). Networks are also shown to influence the information, support and social norms that circulate and operate within networks of PWID, which can positively and negatively impact on risk. As was demonstrated in this chapter, within the hepatitis C sector, research is beginning to explore social relationships more deliberately; particularly those of couples, to better understand how those particular social dynamics influence hepatitis C transmission. However, the influence of larger group networks of PWID on hepatitis C risk and prevention has not been explored in any detail.

This study will report on a identified gap in the literature with respect to social network influences on hepatitis C transmission and prevention, on the explicit assumption that “hepatitis C prevention education [needs to be] better ground[ed] in social relationships” (Fraser et al., 2013, p. 4). To address this gap in the literature, this study will focus on the influence of the social network on hepatitis C-related understandings, communications and network responses to hepatitis C occurring in three networks of PWID. As influence within a social network can potentially take the form of “imitation, emulation, communication, persuasion, pressure and coercion” (Neaigus et al., 2001, p. 221), identifying the social relationship factors that support, or hinder, the knowledge and subsequent behaviour that was both available and acceptable within this study’s networks of PWID was believed to crucial. This thesis will address the gap in knowledge regarding the influence of informal communication generally and the social network norms and dynamics surrounding hepatitis C disclosure specifically in networks of PWID. The next chapter turns to the design and methodology employed in this research, including a description of the qualitative social network approach

employed to most usefully explore understandings, communication, and dynamics relating to hepatitis C within particular social networks of Australians who inject drugs.

Chapter 3 Research design & methodology

This chapter presents an overview of and rationale for the qualitative social network design employed to guide this research. The broad objective of collecting and analysing social network data was to investigate social-network level factors that influenced hepatitis C transmission risk and prevention. In total, 34 participants were recruited to this study but the way their data was included in the study varied. Two different analyses were conducted with different subsets of study participants: a qualitative social network analysis (focused on three of the four networks originally recruited into the study); and a peer distribution sub-analysis (incorporating all collected data). As these two analyses drew on different subsets of study participants, addressed different research questions and employed different data analysis techniques, the two distinctive methodological components of this study are described both together and in separate sub-sections of this chapter.

3.1 Research design

Before introducing the methods employed to conduct the two analyses, it is important to describe the different, although complementary, theoretical orientations and conceptual frameworks that informed this study. These frameworks and orientations not only influenced, but determined, what was considered to be of primary interest during the research, throughout data collection and analysis because the epistemology of these frameworks “guides what you can say about your data and informs how you theorize meaning” (Braun & Clarke, 2006, p. 85).

3.1.1 Theoretical orientation

Theoretical perspectives that informed this study include social constructionism, interpretive interactionism and network exchange theory. Social constructionism is a sociological theory of

knowledge based on the premise that social context is central to the creation and understanding of knowledge (Berger & Luckmann, 2011). A constructionist orientation draws attention to:

The dynamic contours of social reality and the processes by which social reality is put together and assigned meaning. The leading idea always has been that the world we live in and our place in it are not simply and evidently 'there' for participants. Rather, participants actively construct the world of everyday life and its constituent elements (Holstein & Gubrium, 2008, p. 3).

Within this orientation, the ways in which people understand the world they live in is seen to take place within specific social contexts and these settings are viewed as central to the creation, construction and understanding of knowledge (Holstein & Gubrium, 2007). By paying specific attention to the social actions, interactions and reactions that occur in people's daily activities (Mead, 1967) and by building descriptions of these real-life relationships and experiences into the research, a constructionist orientation explores how participants' relationships and interactions play out within a socially inter-connected web of connections, rather than as isolated, individual objects (Robson, 1993). Constructionism therefore views knowledge as situational, contextual and dynamic (Casey & McGregor, 2012) and where multiple, diverse meanings and individual differences in recall and events is expected. As such, there is no simple 'accurate' or 'factual' rendering of reality within a constructionist orientation but rather there are as many, potentially, versions of 'reality' as the number of people involved (Crawford & Marecek, 1989).

Key principles from interpretive interactionism also informed this study. Within this epistemology, emphasis is placed on the importance of social *interactions* in the creation of knowledge and meaning (Prawat, 1996). As social interactions and processes do not happen spontaneously or in isolation (Blumer, 1986), an interpretive interactionism perspective builds upon, or is consistent with, constructionism, but it adds the idea that meaning is produced through exchanges and encounters with others, and certainly is come to be known through interactions. The main way in

which constructionist and interpretive theoretical orientations informed the design of the study was through their focus on identifying and discussing significant social interactions and relationships in order to open up new ways of thinking about how knowledge of hepatitis C is developed, shaped and communicated within specific social network relationships among PWID. Constructionist and interpretive theoretical orientations emphasise the importance of the micro-social environment, the focus of this study, and therefore these orientations were seen as crucial.

The study also draws on principles and methods associated with network exchange theory, which again acknowledges that beliefs, practices and actions do not arise in isolation, but always within an inter-dependent social world (Wasserman & Faust, 1994). Within this theoretical orientation, the way an individual responds to particular issues is believed to be strongly influenced by their social relations and positions in relation to others within their social network (Cook & Whitmeyer, 1992; Emerson, 1976). In this way of thinking, behaviour is more likely to be maintained and reinforced when people within a social network are linked, or mutually oriented to each other (Habib, 2003) because “attitudes and values held by members of one’s social reference group provide information about actions that are likely to be reinforced, supported, and accepted within that social network” (Amirkhanian et al., 2005, p. 59).

With regard to communication, network exchange theories posit that individuals often gain trusted and credible information about important topics through their social networks (Granovetter, 1983): where the nature and type of information that is transferred is seen as strongly linked to the strength of the relationship. Granovetter’s theory of the strength of weak ties, suggests that close and dense relationships result in the forming of cliques, or sub-groups, and these dense sub-groups directly support the sharing of information. However, this theory also suggests that information available to people in dense networks with strong relationship ties is believed to be more restricted than that of

people with weaker relational ties who are thought to have more interactions with a greater number and diversity of people, thereby increasing their access to a wider range of information and sources. Network exchange theory also acknowledges the influence of structure, including external opportunities and constraints (Emerson, 1972a; Emerson, 1972b) that influence individual behaviour and agency. Within this orientation, behaviour, values and social norms are believed to be shaped by social interaction and exchange between individuals (a micro-level influence) and between individuals and society (a macro-level influence) (Emirbayer & Goodwin, 1994). As such, network exchange theory was seen to be complementary to both a constructionist orientation and the risk environment framework that informed this study's design.

3.1.2 Conceptual framework

A risk environment framework was thought to be most appropriate to adequately conceptualise and capture understanding of the context for hepatitis C transmission within social networks of people who inject drugs. The background to this study (Chapter 2) identified how research using the risk environment framework commonly identifies a diverse variety of micro- and macro-level factors, operating in a number of diverse environments, such as physical, economic, policy and social, that influence disease transmission: whilst the micro-social environment remains relatively unexplored by research methods that extend beyond the individual, particularly those focused on social network relationships. This study will therefore focus on the micro-social environment as a specific influence in hepatitis C transmission risk. By describing and interpreting the accounts of PWID with specific reference to their social network relationships, this thesis will explore how social networks shape understandings and beliefs about hepatitis C, hepatitis C-related communication and network dynamics and consider how these factors influence the risk of hepatitis C transmission. This focus on the micro-social environment has not occurred in isolation, as the use of the risk environment framework made it possible to pay specific attention to other environments, which will be discussed throughout this thesis where appropriate.

3.1.2.i Qualitative approach

Examining the micro-social environment through a risk environment framework that extends beyond the individual requires the collection and analysis of relational data, as opposed to focused on individual participant narratives only. As there was little qualitative research available to guide a social network analysis approach, an innovative merging of qualitative research methods with social network analysis was devised. This approach was exploratory, as it attempted to make sense of what 'was going on within the network' (Crossley, 2010), through identifying and discussing the range of network relationships that figured in participant accounts. Informed by the constructionist orientation of this study, a qualitative approach was thought to be most appropriate for identifying those social network influences on the knowledge, communication and dynamics related to hepatitis C risk and prevention: especially those network influences that were not directly observable or those influences not easily identified or quantified (Carpentier & Ducharme, 2007). As such, a qualitative approach was believed to be best placed to be able to elicit a diverse array of people's experiences and conceptions of networks and therefore provide unique insights into a wide range of network influences on hepatitis C risk and prevention.

One of the main reasons for holding an interest in what qualitative approaches might offer to the study of social networks of PWID is that quantitative social network analysis, which dominates almost all research investigations into social networks:

Gains its purchase on social structure only at the considerable cost of losing its conceptual grasp upon culture, agency and process. It provides a useful set of tools for investigating the patterned relationship between historical actors. These tools, however, by themselves fail ultimately to make sense of the mechanisms through which these relationships are reproduced or reconfigured over time (Emirbayer & Goodwin, 1994, pp. 1446-1447).

A qualitative approach to social network analysis was believed to have the potential, therefore, to focus attention more directly on those very issues of culture, agency and process, rather than treating them as 'mere background to biological phenomenon' (Krieger, 2001). Taking a qualitative approach to the analysis of social network data thus involves an attempt to move beyond quantitative counts of pre-defined relationships, structure and resource exchange (Scott, 1991), such as is typical of most large-scale epidemiological studies (Rhodes et al., 2012), to understanding social networks and those important relationships within networks as complex social phenomenon occurring in particular places, at particular points in time.

As with almost all approaches to qualitative research, this study was not influenced by positivist epistemologies, statistical inferences or claims regarding truth, falsity or objectivity in the research (Denzin & Lincoln, 2000). Rather, the question of how to achieve quality was conceptualised in terms of securing 'social structural plausibility' (Auerbach, 2009), particularly through aiming to achieve credibility, and dependability (Guba & Lincoln, 1994) and these two aspects of qualitative research methodology will be briefly discussed here. The relationships and social networks described in this study were deduced from participant interviews and field notes. Only network relationships that were confirmed by at least two people were included in the social network analysis component of the study. This double confirmation of relationships contributes to building credibility regarding the research activities of relationship mapping and defining social network boundaries. Identifying a range of typical and non-typical stories and focussing on both commonalities and variability within the networks, contributes to building dependability in the research. Recruiting a number of distinctive social networks in different geographic locations aimed to achieve insights into both consistency and variance among both individual participants and the various networks. Although a number of consistencies were identified, and these appeared to be remarkably similar across quite diverse social, economic and geographic settings, the findings of this qualitative study were not

intended to be generalised so cannot be claimed to be immediately transferable to understanding and working with other networks of PWID.

3.1.2.i i The networks

Relational indicators used to determine membership and the composition of social network boundaries in this study were informed by the work of Amirkhanian and Colleagues (2005), for whom network boundaries are determined by the inclusion of individuals with ongoing (and stable) proximity to other individuals. This proximity, in most cases, was found to lead to a higher prevalence of social interactions with certain individuals than with others and the stability of these relationships resulted in common, rather than occasional, interaction. Due to an difficulties in identifying and/or contacting all of the social network members named by research participants (as is discussed in detail in the methodology, results and discussion chapters), the networks included in this study may be more accurately described as 'sub-groups' of broader social networks of PWID. The nature, scope and resources available for this study made it possible to capture different social networks at a specific point in time; however, these same resources constrained the capacity of the research to explore historical relationships that may have some degree of influence on the network dynamics among the PWID who took part in this study. As the focus of this study is on those current, densely connected sub-groups, the influence of other relationships, such as those with weaker ties, were not explored in detail and will also not be discussed in detail in this thesis. However, some information on historical relationships and events has been included where this was described by participants as important to understanding their contemporary experiences and relationships.

3.2 Social network analysis methodology

3.2.1 Social network study sites

The social network component of the study was focused on the recruitment of a number of diverse social networks of PWID from different geographic and social settings in NSW. It was assumed that

recruiting social networks from different geographic areas would result in a range of differences in participant socio-demographics, drug markets and service access and availability and varying perspectives on the influence on social network dynamics. It was also assumed that recruiting from different geographic study sites would increase the likelihood that different kinds of social network relationships would be revealed through the interviews, enabling a discussion of potentially different outcomes regarding the relational dynamics for hepatitis C transmission risk (Borgatti, Mehra, Brass, & Labianca, 2009). Participants from four different social networks were recruited to the study, however, due to the extensive scope of collected data and the available timeframe for completion of this doctoral research, only the data from three of these networks were analysed in detail for the social network component of the study (chapters 4-6). These three social networks were located in Newcastle, South-West Sydney and South-East Sydney. Data collected from participants in the fourth network, located on the NSW North Coast network, and for people whose network relationships could not be confirmed in South-East Sydney, have only been included in the peer distribution sub-analysis (see section 3.3 in this chapter for a longer discussion of this sub-analysis, and chapter 7 for the findings).

3.2.2 Social network sampling and recruitment

Sampling is “the acquisition of data from a cross section of a population in lieu of data from each member ... [and] recruitment entails the sampling technique put into actual practice in the course of enrolling subjects into a study” (Kelly, 2010, p. 672). Ultimately, sampling and recruitment are crucial in not only defining who participates in a study and the data available for analysis (Johnson, 1998; Morse, Barrett, Mayan, Olson, & Spiers, 2008), sampling and recruitment processes “provide the basic foundation for what we can say about a social issue regardless of methodological orientation” (Kelly, 2010, p. 672).

Sampling and recruitment are key elements of a study's design, particularly for research involving populations of PWID. PWID are commonly referred to as a hard-to-reach population because of the illegal nature of drug use and as such, may not be visible, easily identifiable or accessible (Wiebel, 1990). A non-probability, snowball sampling technique was employed in this study to access a study population through contact information provided by other research participants (Noy, 2008) in four geographically disparate research sites, which allowed for diversity not only amongst participants but also in social setting. However, it is important to highlight that the utilisation of snowball sampling in this study was "not simply a means of accessing a sample ... [snowball sampling was] central to the topic under investigation" (Biernacki & Waldorf, 1981, p. 53): that is the influence of the social network in hepatitis C harm reduction.

Within each network reported in this study, an initial participant (the key individual discussed in detail below) was recruited who then recruited people within their own social networks to participate in the study. The sampling techniques employed in this study were similar to respondent driven sampling (RDS), in that both snowball referral and RDS sampling techniques use peer-related or chain referral techniques and the use of incentives (Bryant, 2013; Griffiths, Gossop, Powis, & Strang, 1993; Heckathorn, 1997; Paquette, Bryant, & De Wit, 2011; Salganik & Heckathorn, 2004). However, the chain referral techniques employed in this study did not utilise mathematical weighting and modelling, which are typically employed in RDS. Rather, reflecting the qualitative character of this research, this study did not aim to sample a population that could be then considered to be representative of all PWID or all social networks of PWID. On the contrary, purposive snowball sampling techniques were employed in the network component of the study in order to recruit only those PWID who were embedded within a set of social network relationships. Furthermore, the sample size of each social network was not determined by mechanisms sometimes employed in qualitative research, such as the aim of collecting data until a saturation of research themes has been identified, i.e. when no new information is observed in the data (Guest, Bunce, &

Johnson, 2006). Rather, the sample size for this study was more directly informed by the study participants themselves in their identification of relevant and influential relationships during the interview and through subsequent attempts (not always successful) to recruit as many members of those networks as possible to the study.

The recruitment of social networks included three inter-dependent phases. The first phase began with the identification of a service for PWID that could assist with initial recruitment in each of the study sites. Once identified, contact was made with service staff and face-to-face meetings arranged to discuss the study, its aims and methods. All services identified and contacted at this stage of the recruitment process took part in the study. After the service had agreed to take part, the second stage of recruitment process commenced, and this involved the identification of a potential study participant who could act as the 'key individual' in recruiting networks into the study. The key individual was identified based upon their capacity to facilitate recruitment through a snowballing approach, focused on identifying and recruiting other members of their existing social network of people who inject drugs. Given the importance of this key individual for the recruitment phase of the study, service staff were consulted for their views on who might be well placed to invite into the study, focusing on people who frequently attended the service, who had a number of observed social network relationships and would be likely to want to participate in the study and to be able to support the social network recruitment process.

After a key individual was identified at each study site, this person was approached by staff to seek their views on whether they would have any interest in taking part. After a detailed discussion of the risks and benefits of the research, participants provided their consent to participate in the study. None of those invited to join the study as a 'key individual' declined to participate at this stage of recruitment. A semi-structured interview was then conducted with those key individuals, and social network maps were produced with their input, visually depicting the relationships that the

participant regarded as important and influential with regard to their injecting practices. These social maps identified a number of prospective participants and directed the third, and final, stage of the recruitment process.

All study participants were given \$30 for their participation in the study interview, and \$10 for each effective social network referral. The referral payment was paid to the key individual after the completion of the referred participant interviews. It was at this stage of the study that recruitment process differed by study site and therefore these specific details of the recruitment of networks in each site will be discussed in the relevant results chapter. A detailed introduction and background to each specific study site is also contained in introduction of the appropriate social network results chapters.

3.2.3 Data collection

3.2.3.i Semi-structured interviews

All study participants took part in a one-on-one, face-to-face semi-structured interview, which enabled the collection and analyses of the diverse experiences that individual participants brought to the research encounter (Bryman, 2012). These interviews ranged between thirty minutes and two hours in duration and took place in a number of different locations, including in services, libraries, cafes and parks. In all interview locations, participant privacy and confidentiality were deemed to be extremely important and deliberate attention was paid to ensuring these were maintained. The interview questions were developed with reference to the research aims, with specific attention paid to the exploration of the core themes of the research, and any pertinent events relating to these themes. There were several additional influences on both the formation and implementation of the research questions and subsequent interview schedule, including pilot testing of the preliminary interview schedule, and a deliberate investment in reflexivity and flexibility during the course of data collection to ensure interview questions were appropriate and successful in eliciting a

range of information from participants. Interview questions were used as prompts during participant interviews, rather than being overly structured, in order to facilitate a more open-ended discussion of the issues of significance to the participants. This flexibility was viewed as particularly important as it is believed to show “more respect to the feelings of the participants, where more formal methods may be inappropriate” (Padgett, 1998). It is also important to note that the participant interviews conducted as part of this study were not in-depth life-history interviews. However, they did explore a range of social and historical issues for participants, such as housing, disability, age, and relationships, and these contextual and background issues will be discussed where appropriate. A copy of the full interview schedule is contained in Appendix B and further discussion and reflections on the methodology used in this study will be discussed in Chapter 8.

3.2.3.ii Participatory social network mapping

Due to the importance placed on understanding how the individual participant described membership of their social network, collection of relational data was particularly significant in this study. Social network analysis involves visually identifying, and subsequently representing, the most important and relevant social relationships to an individual (Beazley & Ennew, 2006). This mapping exercise is most commonly referred to in the quantitative social network analysis literature as the production of ‘sociograms’. However, the term ‘participatory social network mapping’ was developed as a more appropriate concept for the qualitative approach to social network analysis adopted in this study. The production of social network maps began in the first part of each interview, where names and social network connections were elicited by asking the participant who they had injected with in the previous week/month and who they had talked to about hepatitis C. These people were then sketched onto a piece of paper by the researcher, so that the participant could assist in refining the illustration to ensure it reflected their perspective as accurately as possible. Additional relationships were added to the map as the participant answered individual research questions. Mid-way through the interview process, the map was shown to the participant,

who was then asked if any major social relationships were missing. Following this, the interview further explored the identified relationships with respect to hepatitis C understandings, communication, and social network dynamics relating to hepatitis C.

3.2.3.iii Field notes and observations

Observational data was also incorporated into the research in the form of field notes collated during the periods in which interviews and mapping exercises were conducted. The focus of observational field notes were the relational interactions and communication dynamics between participants, particularly when participants accompanied other network members to their interviews. These observations also assisted in the development of the participatory social network maps and subsequent recruitment processes, as these notes identified possible social network connections that could be drawn on for the study and in recording any important network-related issues arising during the interview. Reflective field notes were also recorded after each interview had been concluded and these notes included identifying different language and terminology used to describe injecting equipment and practices. These language and terminologies were then used in subsequent interviews within the network, thereby ensuring that interview questions were understood by different study participants and that the data could be appropriately organised for subsequent data analysis.

3.2.4 Data analysis

All interviews were transcribed verbatim by a professional transcriber and all data was organised, coded and analysed with the assistance of NVivo (V9) qualitative data analysis software. Interview transcripts were checked for accuracy against the recordings and during this process, individual transcripts were also 'cleaned' to remove identifying data. Important observations and project notes from the field diary were also entered into the relevant participant cases in NVivo. This was a key phase in the data analysis process as the notes and reflections identified during the data collection

and transcription phase fed directly into the identification of important relationships and the codes to be used during the thematic analysis.

3.2.4.i Thematic analysis

Thematic analysis, whereby individual participant interview transcripts were read and re-read with a view to identifying patterns of meaning across the data set (Patton, 2002), was the first analysis undertaken. The approach to thematic analysis employed was both deductive and inductive. A deductive thematic analysis was undertaken to explore the core research domains – understandings, communication and network dynamics – which were pre-defined prior to data collection and subsequently directed the first round of coding and analysis. During this approach “themes were identified in explicit or surface meanings of the data, not looking beyond what a participant had to say” (Braun & Clarke, 2006, p. 184). However, an inductive thematic approach was also employed, to make full use of the breadth and complexity of the data. This approach enabled the identification of themes that were unexpected, or that emerged in relation to the main domain areas. This approach also made it possible to identify factors that influenced the core themes in greater depth, including those reporting on social network dynamics, wider social influences such as hepatitis C-related stigma and discrimination and the practice of peer distribution. Direct quotes were employed in the reporting of the thematic analysis findings to highlight the range of perspectives provided and to enable the reader to see the relationship between participants’ understandings of the key issues and the interpretation proposed by the researcher.

3.2.4.ii Relational analysis

To achieve meaningful insights into the operation of social networks, individual network members and their particular experiences and viewpoints needed to be linked to the people with whom they had relational ties and the events that participants identified as most influential. In this study, matching of relationships was directed by the mapping of participatory social networks and the coding of interview data. Relational matching was undertaken in a two-part process, including the

identification and analysis of person to person relationships (known as a 'dyad' in quantitative approaches to social network analysis) and sub-group relationships (i.e. how an individual relates to a sub-set of the entire social network).

Data analysis at the person to person (dyad) level

Once individual interview transcripts had been thematically analysed, the data was also analysed at the dyad-level, which involved matching and comparing the accounts of pairs of individual participants who were relationally tied to each other. The person to person relationships included in this study comprised social relations, injecting relations and sexual relations, or a combination of these. Data analysis included the documentation and assessment of communication ties, such as who exchanged information with whom, the type of information exchanged, and any similarities and differences that were evident between the knowledge, beliefs and practices of these two network members. In addition to communication ties, material ties, such as who shared financial resources, who gave sterile injecting equipment to whom and who assisted others in the injecting episode, and inequalities between these ties, was also analysed.

Data analysis at the sub-group level

Data analysis at the sub-group level was also undertaken because it was believed that this analysis would lead to a better understanding of the social context in which information exchange and diffusion occurred across groups (Hersberger, 2003). Analysis at the sub-group level was also thought to be important in understanding the complexity and network dynamics that occurred in different sub-group settings. The sub-group analysis involved the analysis of the similarities and differences within and between network sub-groups. For example, analysis at the sub-group level paid particular attention to instances where communication, knowledge and/or resources did or did not flow within networks and their sub-groups, as well as appraising the positive or negative influence of the network and particular sub-groups on hepatitis C risk and prevention.

Presentation of social network results

With respect to the presentation of the results, a choice was made to describe and interpret specifics of the data analysis in the respective network results chapters but to then defer discussion of the conceptual and empirical implications to the final chapter. Within each of the network chapters, the results will therefore be presented by describing the key network characteristics, including the setting, recruitment process, main network members recruited to the study (descriptions of their social backgrounds and circumstances and their drug use) and network relationships. Each network chapter will then report on the findings generated in each of the core domains of the research, that is, hepatitis C-related understandings, communications and network dynamics. A summary of each network is provided at the end of each network chapter and the discussion (Chapter 8), synthesises these findings across the networks.

3.3 Peer distribution sub-analysis

A consistent theme emerging throughout the data collection process related to peer distribution, that is, the distribution of sterile injecting equipment within social networks of PWID. As it appeared that this theme was both dominant and topical amongst the networks that took part in the study, additional research questions were developed during the course of analysis to investigate this practice in more depth. These questions included:

1. What roles did individual PWID assume in peer distribution practice?
2. Were specific relationship pathways evident in peer distribution?
3. Could peer distribution activity be measured?
4. Were study participants aware that it is illegal to participate in peer distribution in NSW?

3.3.1 Sampling and recruitment

The peer distribution sub-analysis included the recruitment and participation of four social networks, which were geographically located in Newcastle, South-West Sydney, South-East Sydney and the NSW North Coast. The recruitment of participants for the peer distribution sub-analysis was part of the overriding snowball sampling technique and the initial contact from each of the four networks reported in the peer distribution sub-analysis reflected the snowball sampling processes described in the network analysis: that is where a service was contacted and a key individual identified, recruited and interviewed. This key individual then referred members of their social network to the study. However, unlike the social network analysis component of the study, where participants were required to be relationally linked, the analysis of peer distribution data included all participants who described participating in peer distribution, regardless of network relationships.

3.3.2 Thematic data analysis

Analysis of peer distribution was also undertaken using a thematic analysis of the different peer distribution roles, the relationship pathways in which peer distribution occurred and participants' knowledge of the illegality of peer distribution. To determine the patterns, context and roles involved in peer distribution, participants were asked who they distributed or received sterile injecting equipment to and from, to what extent and why? The peer distribution roles were initially conceived as including the distributor role (distributed equipment only), recipient role (received equipment only) and reciprocal exchange role (received and distributed equipment); roles also identified by Bryant and colleagues (2009). However, the need to refine the distribution role became evident during analysis as this role appeared dependent on the scale of activity and the motivations behind the distribution. Therefore, the peer distribution roles included in this analysis included formal distributors, those people who distributed large quantities of sterile injecting equipment, and informal distributors/recipients. These roles were not described as such by the participants

themselves in explaining their peer distribution activities, nor were they roles that have been identified in the research literature previously.

Within the informal distributor/recipient role, a thematic analysis was conducted to examine the distribution pathways of peer distribution. These pathways included peer activity occurring between close family and friends, between people living within close proximity with each other and between dealers and their customers. Another relationship pathway, that is the distribution of sterile injecting equipment between acquaintances, was identified during data collection and subsequently added to the complete list of relationship pathways. Due to the informality of peer distribution exchanges occurring within the informal distributor/recipient role, an estimate regarding distribution size, such as the estimate calculation used to determine the size of the formal peer distribution role (discussed in the next section), could not be made for informal distributor role. Details of the formal role will be discussed in the case study analysis.

3.3.3 Identifying case studies

A case study design was thought to be the most appropriate to report on the formal peer distributor role because this design is able to explore the situational and contextual factors that are important for understanding and explaining this role (Yin, 2008): a role that has not been documented previously in the research literature. The formal distributor case studies reported in this study had to meet a number of criteria for inclusion. Formal distributors were characterised as PWID who collected large quantities of sterile needles and syringes (over 100 syringes at any one time) and distributed over 50% of equipment collected to other PWID. The role also included the distribution of other injecting equipment, such as spoons, filters, swabs and water ampoules, and the collection and disposal of used injecting equipment. Formal distributors were characterised by the participant's own definition of themselves as a person who provided ongoing and frequent access to sterile injecting equipment to other PWID, and/or as a person that other PWID identified as

someone from whom they could access sterile injecting equipment. Therefore, the distribution of sterile injecting equipment via the formal distributor role was a defining characteristic of that individual's injecting-related practices, not just a casual activity.

Five formal distributor case studies were developed to capture the various aspects of this role, including an estimation of the annual peer distribution activity and a description of the motivations they explained as being behind their peer distributor role, and the types of PWID receiving equipment from them. To better understand the formal distributor role, detailed analysis was conducted on the specific practices of the role, motivations for participating in large scale distribution, types of people that they distributed to and harm reduction information that they exchanged during peer distribution. To estimate the annual peer distribution of formal peer distribution, the following process was employed: identification of the number of needle and syringes (and other injecting equipment) that was collected by the individual each week; identification of the number of personal injections per week; and calculation of the difference between equipment collected and amount estimated for personal use. This estimation included the assumption that all equipment not used for personal use was distributed. Estimating the number of needles and syringes distributed was seen to be important because this estimation made it possible to assess the potential effectiveness and viability of formalised peer distribution as an alternative mode for distributing sterile injecting equipment in NSW.

3.4 Ethical considerations

The study received ethical clearance from the University of New South Wales (UNSW) Human Research Ethics Committee (HREC) approval (no 09022). A copy of this approval is contained in Appendix C. During data collection, two study sites were added to the study design and the amendment for site inclusion is contained in Appendix D. Appendix E contains a copy of the participant information statement. In all interview locations, privacy and confidentiality was

paramount and prior to the commencement of interviews, informed consent was sought and all interviews were conducted and digitally recorded. All research data collected in this study was managed in accordance with the UNSW procedure for data storage and retention of research material and state-based legislation, the Privacy and Personal Information Protection Act 1998 (NSW). Other important ethical considerations for this study included participant care, payment for research participation and confidentiality and de-identification of data, which will now be briefly discussed.

Participant care was paramount in the research design and implementation. Prior to interview, a list of appropriate health and injecting-related services was compiled for each study site and taken by the researcher to the interviews. Referrals to individual services were made for participants dependent on individual needs and a debriefing was conducted with every participant at the end of their interview. During this debriefing, information was provided to the individual regarding information and knowledge gaps about hepatitis C transmission that were identified in the interview. A payment of AUD\$ 30 was provided to all participants to compensate for time taken to participate in the study and a further payment of AUD\$ 10 was provided to participants who effectively referred another person to the study as recompense for costs associated with contacting friends for recruitment. As this payment was made after successful interviewing of the referred participant, the referee typically brought the social network member to the study interview. There is some debate about the use of financial incentives in human research because of the undue influence or coercion that these payments (are thought by some) to offer (Grant & Sugarman, 2004). However, peoples' motivations for participating in research have been found to be more than financially incentivised and other motivations can include "interest in or curiosity about the research topic, anticipated rewards to self and others and the desire to access information" (Fry & Dwyer, 2001, p. 1323).

In this study de-identification of all data was very carefully applied. This included the creation of pseudonyms for all study participants and the removal of any other identifying information to protect participant privacy and anonymity. During the interview process, participants generated 'codes' to identify social network members in the form of nicknames and/or initials. If participants suggested the use of real names of other participants, including in other networks, those suggested codes names and any potentially identifying information was removed during the data cleaning phase. Social network analysis designs have revealed a range of broader ethical issues, including the importance of preserving anonymity in the way network findings are collected and reported (Borgatti & Molina, 2005). Study participants' privacy and anonymity was managed in this study within the data collection phase, by not re-telling stories provided by other research participants or prompting for particular people or events that had been mentioned previously by other network members. A more detailed reflection on the social network analysis methodology used in this study is described in the methodological reflections section in Chapter 8.

3.5 Summary

This study investigated social network influences on hepatitis C transmission via a qualitative approach to social network analysis, an area which has been underexplored in the research literature to date. The research was informed by and sought to contribute to knowledge on the risk environment framework, which is believed to be the most appropriate framework for guiding exploratory qualitative research in this area. Having a clear sense of the theoretical and conceptual influences on this research made it possible to collect, analyse and report on the complex range of details revealed through this research. The following chapters (4-6) present the results of the social network analysis of data collected at the three primary study sites. Each of these results chapters begins with providing an overview of the site including providing background on the setting. Details related to site specific recruitment processes are provided next, followed by, an introduction to social network members and the relationships between these members. Each chapter will then turn

to the thematic analysis for that network, exploring the influence of social network relationships with respect to hepatitis C understandings, communication, and social network dynamics. The Newcastle network is discussed first.

Chapter 4 Newcastle network

4.1 Study site overview

4.1.1 The setting

The Newcastle study site is a large metropolitan area in the Hunter-New England district of NSW, consisting of the Newcastle city centre, the residential beach suburbs in East Newcastle, Newcastle Harbour and a number of suburbs adjoining, or west of, the Newcastle city centre. Newcastle is geographically situated on the east coast of Australia, about 150km north of Sydney: it is the second largest city in NSW, after Sydney. In 2011, Newcastle had an estimated population of 148,531 (Australian Bureau of Statistics, 2011b): where 83% of the Newcastle total population were born in Australia and of these 3% identified as being of Aboriginal descent (Australian Bureau of Statistics, 2011a). Of the 17% who were not born in Australia, the largest group of people migrating to Newcastle came from the United Kingdom (Australian Bureau of Statistics, 2011b).

The Newcastle area has a long history of economic dependence on heavy industry, such as coal mining and steel exporting. Coal was discovered in Newcastle in 1799 (Martin, 1991) and a penal colony was established in 1801 to mine the coal (Turner, 1982). Newcastle is now the largest coal exporting harbour in the world (Fickling, 2010). Steelworks were established in 1915 and at its peak; the steel industry employed 13,000 workers. However, in 1999, the steel works were closed, representing Australia's largest industrial shutdown at that time (Marciniak, 2000). Another important event that shaped the Newcastle area was the 1989 earthquake, which had an epicentre close to the city centre. This earthquake left the city with a damage bill of "\$AU 4 billion, including damage to 35 000 homes, 147 schools, and 3000 commercial and other buildings" (Commonwealth of Australia, 2004). As a result of the earthquake damage, there was significant withdrawal of

investment in the area and movement out of the inner-city, and many blocks of land which were demolished due to a lack of safety were not rebuilt.

On a more positive note, there has been some recent re-investment in the coal sector in Newcastle, due to commodity price increases. In addition, significant investment has occurred over the last decade to rebuild areas damaged in the 1989 earthquake, including the residential and commercial areas of Newcastle Harbour, Newcastle East and the Newcastle city centre. By comparison, the surrounding and outer-western suburbs of Newcastle have received little attention and investment as part of Newcastle's recent growth. These areas of Newcastle are predominantly residential and almost 21% of people residing in these areas live in public housing estates (Australian Bureau of Statistics, 2006). Referred to as 'public housing ghettos' by Newcastle city residents (City of Newcastle, 2011), areas such as these which are dominated by housing provided by government to people on low incomes are not unique to Newcastle or Australia, and their design often co-locates people with low average incomes, low levels of educational attainment and high rates of unemployment, contributing to the long-term reproduction of particular geographic areas of social disadvantage (Randolph & Holloway, 2005).

The Newcastle study site featured a number of Needle and Syringe Programs (NSP) that were delivered through a range of service models. These included a primary NSP based at a hospital in the outer suburbs and another primary NSP near the city centre. In addition, a number of prominent NGOs have also established secondary NSPs in their community health services, specifically aiming to provide access to sterile injecting equipment to young people, Indigenous Australians and gay, lesbian and transgender people. Access to sterile injecting equipment was also provided by a number of pharmacies in the Newcastle area. Other harm reduction services for PWID, such as methadone maintenance for opioid dependence, were not well serviced in the Newcastle area. As Dr Adrian Dunlop, Director of Drug and Alcohol services in the Hunter New England Local Health District

explained when he was interviewed by the Australian Broadcasting Commission (ABC) series *Hooked on Heroin*, which the ABC aired in response to an eminent global commission roundtable on Australia's drug policy (see Douglas & McDonald, 2012). Dr Dunlop explained:

There's unfortunately a two-year wait for people trying to get treatment for heroin addiction in Newcastle ... An estimate of somewhere around 500 to 600 people I think we could send up for treatment tomorrow if we had the capacity to do so ... I have never heard of a wait this long in a developed country (McMahon, 2012).

Dr Dunlop's concern not only highlighted the need for methadone maintenance in the Newcastle area, it also identified how funding for PWID services in NSW was not always based upon demand. For example, Dr Dunlop also noted that, in contrast, there would be only a two week waiting list to enter a methadone maintenance program in Sydney, Wollongong or Lismore. Aside from large research projects (O'Brien, Day, Black, & Dolan, 2008) and surveillance (The Kirby Institute, 2011), no research in which results could be disaggregated was found to provide further insight into the experiences of PWID from the Newcastle area.

4.1.2 Recruitment

The recruitment process in the Newcastle study site was initiated with advice from a Sydney-based PWID organisation that identified contacts with PWID in the Newcastle area. The key individual recruited to the study site has been allocated the pseudonym of 'Natasha'. After interviewing Natasha it became apparent that she did not want to recruit her social network members to the study due to what she felt was an inability to remain anonymous in the study given her role in the wider drug scene in the Newcastle area. However, Natasha wanted to assist the study and so provided an introduction to a youth service that provided secondary NSP in Newcastle and therefore Natasha is not included in the Newcastle network results. The staff of the youth service agreed to participate in the study and subsequently identified Chris as a possible study participant. Chris agreed to participate in the study, and all further recruitment was then managed directly by the

researcher, without the assistance of the youth service. Chris first contacted Tim and Jayde. Tim attended the interview with his girlfriend, Sue, who was also willing to participate and so she was interviewed immediately after Tim. Although Jayde and Chris were not friends and did not inject or socialise together, they knew each other as acquaintances through attending the same youth service to obtain sterile injecting equipment. Jayde was recruited and interviewed, however, she chose not to recruit her sub-group to the study because she believed they would be embarrassed and would not want to talk about drug use with a person they did not know. A number of attempts were made to recruit other members of Chris' subgroup, specifically Phillip, John and Brad, however, these attempts proved unsuccessful.

4.1.3 The main network members

The Newcastle network comprised at least eight individuals known to be socially inter-connected, four of whom participated in the study. The Newcastle network membership could be described as young, with little formal education and unemployed at the time of interview. This membership also included both heroin and methamphetamine injecting sub-groups. All network members were receiving social security as their main form of income and all were living independently and in public housing, with the exception of Jayde who lived with her grandmother in a privately rented house. All were tested for hepatitis C and reported as hepatitis C negative, except Jayde who had not been tested. None of the Newcastle network members had participated in research before.

Chris was a 21 year old Anglo-Australian male. Chris started injecting heroin at 11 years of age. Chris identified as a 'recreational drug user' and injected as much as he could afford, with his last injection two weeks prior to interview. Chris had a good relationship with staff at a local youth service and used this service to access his injecting equipment. Although Chris had spent a good part of his life living on the streets in Newcastle and Sydney, at the time of interview he was living in a public housing apartment with his pregnant girlfriend. Chris was also the father to three young children

from a previous relationship. Chris left school in first year of high school, aged 12: he could not read or write. Chris also spoke of mental health issues, was unemployed and received youth allowance as his main source of income. Chris had a hepatitis C test every six months and self-reported as hepatitis C negative.

Tim was a 17 year old Anglo-Australian male. Tim started injecting methamphetamine (speed) at 14 and heroin soon after. At the time of interview, Tim would only inject heroin and morphine and he did this as often as could afford, which was generally every two to three days. Tim only injected with his girlfriend, Sue, and friend, Brad, and the injecting episode would most commonly occur at Brad's home. Tim explained that he was initially a "bit cautious at first [about obtaining injecting equipment from NSPs] but they're alright now", however, Tim was still somewhat reliant on others for accessing injecting equipment because he would not attend services himself, which was explained in terms of convenience. Tim left high school in Year 8, aged 13. Tim had spent time in juvenile detention and a psychiatric facility, where he was housed when he was 15 for drug-induced psychosis. Tim's main source of income was a disability pension. Tim was in a sexual relationship and lived with Sue. Tim had been tested for hepatitis C two years prior and self-reported as hepatitis C negative.

Sue was a 16 year old Anglo-Australian female who had started injecting heroin at 13. At the time of interview Sue injected heroin and morphine, two to three times a week with Tim and Brad. Sue was reliant on others for accessing injecting equipment because she would not attend services herself after she had been refused access to sterile injecting equipment from pharmacies in the past, perhaps because she appeared extremely young to pharmacy staff. Sue also spoke of alcohol use, although the extent of alcohol use was not made clear during the interview. Sue completed Year 9 high school and left formal education, aged 15. Sue identified as bisexual and had been in a heterosexual relationship, and lived, with Tim for one year. Her main source of income was youth

allowance. Sue had been tested for hepatitis C eight months prior to interview and self-reported as hepatitis C negative.

Jayde was a 17 year old female who identified as Aboriginal, that is, as having a cultural identity that connected her to the indigenous Australian community: Aboriginal and Torres Strait Islander peoples. Jayde began injecting at 14 and at the time of interview injected methamphetamine ('speed') and ecstasy as often as she could afford, ranging from not at all to up to three times a day. Jayde would inject with her ex-girlfriend, her sister or another male and the injecting episode was most likely to occur at Jayde's place or her sister's house. Jayde had a good relationship with staff at a local youth service and used this service to access her injecting equipment. Jayde also spoke of excessive alcohol use and had a number of competing health issues, including self-harming through cutting. Jayde's main source of income was youth allowance. Jayde had left the education system after completing Year 9 high school, aged 14. Jayde lived with her grandmother. Jayde had not been tested for hepatitis C.

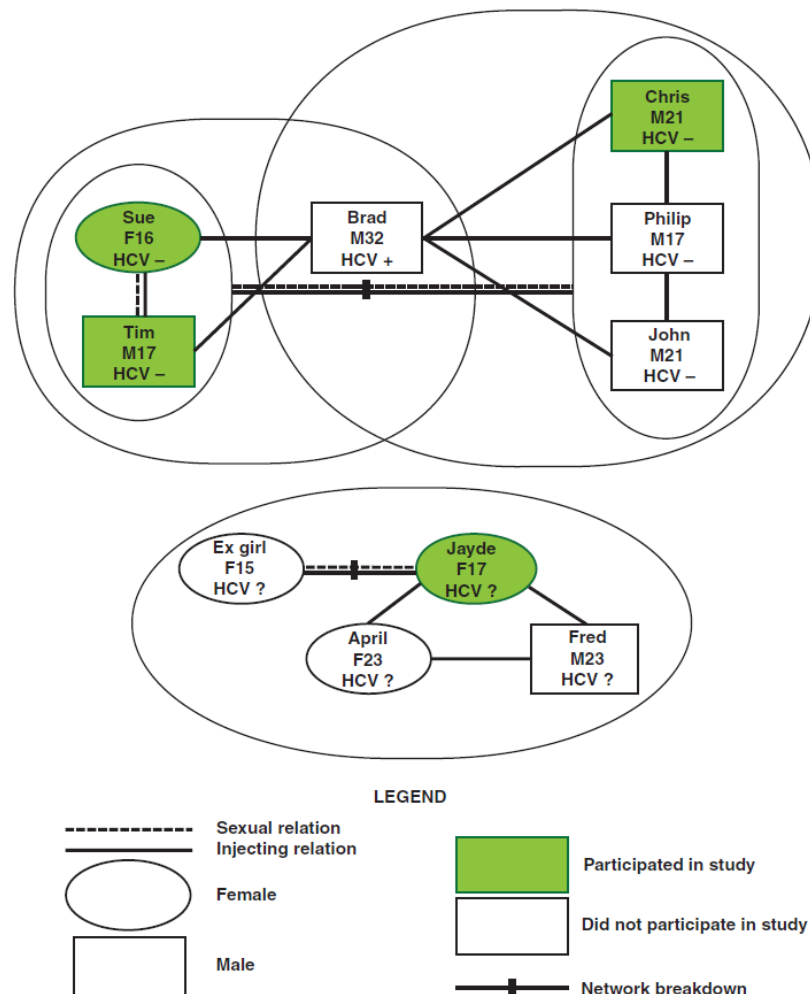
Other people were identified by the Newcastle network members as being important to the networks' knowledge, health and injecting practice. Jayde identified her sister, April, April's boyfriend, and another male who she had injected and socialised with. Chris, Tim and Sue identified Brad, a 32 year old Anglo-Australian male, who they injected and socialised with. Chris also identified his brothers as important in his social network. However, as these people did not participate in the study, they will be referred to where appropriate, but only via the accounts provided by the participating members of the Newcastle network.

4.1.4 The network relationships

The Newcastle network contained three distinct sub-groups, including one stimulant based sub-group and two heroin based sub-groups. The first sub-group included Tim, Sue and Brad; the second

sub-group included Chris, Brad and Chris's brothers and the third sub-group included Jayde and her sister. The current network relationships are contained in Diagram 1 and detailed description of these relationships is discussed after the diagram.

Diagram 1 Newcastle social network and sub-groups



Chris and Tim had known each other for a number of years. They had both lived in an abandoned property, known as a squat, with Chris's brother's John (M21) and Phillip (M17). During this time Chris, Tim, John and Phillip would inject together. Brad also formed part of the network during this time, however, the extent of his participation was not made clear by other Newcastle network

members due to the focus of the research on current relationships. Sue met Chris and Brad, approximately one year prior to when she began dating Tim. During this time Chris, Tim, Sue, Brad, John and Phillip were more likely to inject as a larger group. Approximately three months prior to interview, this larger sub-group split because of a sexual affair between Chris and Sue. This split resulted in two new sub-groups forming. The first sub-group included Tim, Sue and Brad. The second group included Chris, his brothers and Brad. As a result of the network breakdown, Tim and Sue do not speak to Chris and vice versa and Tim and Sue would only inject drugs with Brad. Social relations between Tim and Chris's brothers had also broken down.

Jayde was a member of a stimulant based sub-group. Jayde injected with her ex-girlfriend who was 15, her 23 year old sister April and April's boyfriend. Jayde had also injected with a 20 year old male, however, he had recently moved away from the Newcastle area and so Jayde no longer injected with him. Jayde also spoke of a number of other friends who did not inject drugs and who would not socialise with Jayde since her injecting drug use became known. Jayde had met Chris at a local service where they both spent time and accessed sterile injecting equipment. However, they did not socialise or inject with each other.

4.2 Hepatitis C-related understandings

The following section will describe the Newcastle network members' knowledge and beliefs about hepatitis C risk, prevention and treatment and consider how these understandings seem to have been developed and shaped, and how they relate to accepted understandings, including the level of seriousness ascribed to hepatitis C.

4.2.1 Knowledge about hepatitis C

All Newcastle network members were aware of hepatitis C and most knew it could be transmitted through the sharing and reuse of needles and syringes. However, for some this knowledge was only

recently acquired, and the risk of transmitting hepatitis C via other injecting equipment was not well described. When describing their knowledge, Newcastle network members were more likely to discuss hepatitis C in terms of generalisations rather than recalling specific knowledge about transmission or treatment. The rest of this chapter will explore these observations in detail. Significant time delays were reported by all Newcastle network members regarding when they first came into contact with even the most basic hepatitis C information. Chris explained how it had taken eight years after his initiation to injecting to come into contact with information about hepatitis C:

No to be quite honest it weren't until about two to three years ago that I first like really got to know more about hep C. Yeah [the first time I heard something about hepatitis C was] when me mate came back after he'd tested positive. I knew what [hepatitis C] was but I didn't know like exactly what it was. I knew it was a disease that's it. I just thought it was pretty much like syphilis, just comes and goes (Chris, M21).

Chris's illiteracy meant he was particularly reliant on others to inform him about hepatitis C and he explained how the first encounter he had with information about hepatitis C resulted from Brad's disclosure of a positive hepatitis C diagnosis. At the time, Chris explained that he believed that hepatitis C was a disease that "just comes and goes"; seeming to imply that this meant hepatitis C wasn't something that was to be particularly feared. Chris' explanation also included the belief that hepatitis C was similar to syphilis, which again was represented as something not to be feared.

After Chris's first encounter with information about hepatitis C, he explained that he had consciously chosen to learn more and that he now understood hepatitis C transmission as:

Blood-to-blood. I always been like, always thought and got told it was blood to blood, saliva contact or sharing. [Transmission risks include] needles, tattooing, unsterile things that puncture your skin. Oh well if one person's got hep C and they've got a cut on them and you got a cut on you and it touches you can get it that way.

[Interviewer: Spoons can transmit hepatitis C] Can they? I've been told about the cups of water from me grandfather, he was a medic and he taught me a lot about sterile and tools. No. I've never heard about [a] spoon transmitting hep C. I will be using new stuff, even me spoon. Yeah you wouldn't think of it [spoons being a transmission risk] (Chris, M21).

Chris' understandings of hepatitis C transmission risks were focused on anything that punctured the skin. He incorrectly named saliva as a transmission risk and was not aware of the risk posed from the spoon used in drug preparation. This information surprised him because Chris believed that he was adequately informed about hepatitis C transmission risks, because he had sought information about these risks from his medically trained grandfather. When I noted the transmission risks associated with spoons at the end of the interview, Chris indicated that his behaviour would change as a result of that new information and that he would no longer reuse spoons in the drug preparation process. This exchange reveals how important it was to Chris to feel that he held accurate knowledge regarding the risks associated with injecting.

In relation to hepatitis C genotypes, Chris explained that his understanding of hepatitis C included the belief that hepatitis A, B and C represented different strains of the same virus. Chris explained: "I just thought that hep A, hep B and hep C were just like the same disease but different strains. That's all I thought, I didn't know there'd be little bits off that". Given this explanation, the inclusion of saliva in Chris's account of hepatitis C transmission risks became clearer: saliva was included in Chris' account because of confusion about transmission risks from all of the different varieties of viral hepatitis.

Sue recounted how her knowledge of hepatitis C had been developed whilst attending high school:

I knew a bit of it [hepatitis C] because of school. Yeah they taught it [hepatitis C] through PE [Physical Education]. The teacher told you about what drugs can do to

you and about harm stuff. Well we got taught like different ways you can get hep C, how to treat it, all that kind of stuff. Yeah, I listened to every single bit of it. I've been careful about what I do (Sue, F16).

Sue presented as knowledgeable about hepatitis C during the interview, and also as someone who was keen to understand transmission risks. Although Sue stressed that she had listened to hepatitis C information delivered at school, she did not provide any specific or detailed knowledge regarding transmission or treatment with the exception of saying that this information had increased her vigilance in injecting settings, after which she became 'more careful'.

Sue also explained that she had been tested for hepatitis C and that she had discussed the risk of acquiring hepatitis C with health professionals at that time:

I just thought I should get checked up. Yeah [at the local doctor]. Yeah they were alright. They [explained what hepatitis C was] and gave me information. I already knew about it and then they said about using needles and stuff like that, and they said 'are you cleansing' and I go 'yeah' and they say 'that's cool, we'll give you a test' and it came back clear. [They told me] just like 'don't share needles' and things like that, [and if] 'you share needles and you might possibly have hep C' and all that kind of stuff and I'm like, 'I already know' (Sue, F16).

During hepatitis C pre-test counselling, Sue recalled that the person who had administered the test had discussed hepatitis C, including the transmission risk of sharing and reusing needles and syringes. Interestingly, Sue also explained that the health professional had asked her if she was 'cleansing' and it is assumed that this may have been the professional asking if Sue had been cleaning equipment. Sue did not recall the delivery of other transmission risk information, including the risk of other injecting equipment. The omission of this information may have resulted because Sue presented as knowledgeable about hepatitis C and therefore this portrayal may have affected the amount and type of information provided by the health worker during pre-test counselling.

Alternatively, health care workers may not be delivering specific information during pre- and post-test counselling, or least not in every such encounter.

When describing hepatitis C-related knowledge, Jayde spoke only in terms of generalisations:

You can transmit [hepatitis C], oh it's basically blood to blood and I'm just going off what was put into my head. It's blood to blood yeah something or other big word for it and it's like a virus and you wouldn't know you had it until you went and actually had the test for it. It's not that noticeable really. You wouldn't pick it out if it was there and if it's not found out about it you could go for years and unless something goes wrong. [You would know if you had hepatitis C because] you have a test in the hospital. They give you a blood test and automatically they know you use. They'll take a blood test and they'll test it on how many drugs you've been using (Jayde, F17).

Jayde understood that hepatitis C was a blood-borne virus and had previously explained that she received this information at school and from the local youth centre. Jayde also believed hepatitis C was asymptomatic, suggesting a person may not know that they had contracted the virus until they were tested. Furthermore, Jayde believed that hepatitis C testing was also used as a drug use surveillance tool and this could have influenced Jayde's willingness to be tested for hepatitis C. Although Jayde did not identify transmission risks in response to the interview question about knowledge, she did explain during the interview that she did not share injecting equipment, including needles, syringes and spoons with her friend that was hepatitis C positive, indicating that she was aware of most of the accepted transmission routes of hepatitis C.

Tim had been tested for hepatitis C, approximately two years prior to interview. He explained that when he was in a psychiatric institution he had been required to undertake compulsory hepatitis C testing, explaining that "they just said oh we're gonna check you for hep C, we need to take your

blood”. I asked Tim if he was aware of what hepatitis C was at that time and he said “Oh, I had an idea”. However, when Tim was asked further questions, it became clearer that he held very little knowledge about hepatitis C or its treatment:

Oh I know it’s a blood transmitted disease, that’s about it. I heard there’s no cure for it... I have heard one discussion and they said it would cost \$30,000 or something to get it treated or something (Tim, M17).

Although Tim was aware of hepatitis C and that it was a blood-borne virus (identified as a disease), he did not explain what this meant in relation to hepatitis C transmission risk. Tim also explained that he was aware there was treatment available for hepatitis C; however, he did not think there was a cure. This belief was interesting because he had overheard other PWID talking about the cost of hepatitis C treatment, which Tim could not afford and therefore Tim’s account of hepatitis C included the belief that hepatitis C could not be cured.

4.2.2 Beliefs about the seriousness of hepatitis C

All Newcastle network members were asked if they believed hepatitis C was serious and/or a priority for them. The various perceptions of Newcastle network members regarding seriousness have been organised into three thematic categories: comparing the seriousness of hepatitis C to HIV; hepatitis C as serious but situational; and no opinion on the seriousness of hepatitis C.

Chris and Jayde believed that hepatitis C was serious; however, when hepatitis C was compared to HIV, they viewed hepatitis C as less serious. Chris explained:

Hell yes [hepatitis C is serious]. Apart from AIDS, it would have to be one of the worst diseases. Yeah, see blood transmitted diseases really scare the livin’ crap out of me. Yeah that’s why it scares me, blood transmitted diseases are diseases you can’t see; anything I can’t see I’m petrified of (Chris, M21).

Chris's account of the seriousness of hepatitis C was prioritised against, and below, HIV (which he described incorrectly as AIDS). Although the basis of this prioritisation was not clear, Chris's perception of the seriousness of both HIV and hepatitis C appeared to be deeply influenced by his general fear that blood-borne viruses may not always be visible to the naked eye. It is interesting to observe this belief that a 'hidden' disease being scarier than those that can be 'seen', which was not articulated by any other participants.

Jayde explained her views on the seriousness of hepatitis C by relating an experience she had had with a friend who had tested positive to hepatitis C:

My mate comes up and says 'oh like I've got hep C', you don't know what it is. You think it's something close to AIDS don't ya. So you freak out like 'oh I don't want to get it, I don't want to get it'. That's the general reaction you get. That's kinda like why I stopped talking to him for a couple of days. I reckon he'd feel bad ... No I never asked him [how he felt] but I reckon he'd feel like a bit ashamed and really bad and sad about it. I felt a bit bad and I felt really sorry for him (Jayde, F17).

In this quote, Jayde explained that she had not known how to respond to a friend who had disclosed he was hepatitis C positive. Within this explanation, Jayde explained that at the time she believed hepatitis C was as serious as AIDS and that that this belief was (in part) responsible for her not dealing with her friend's disclosure in a knowledgeable or supportive way. Although Jayde was empathetic towards her friend, she believed her initial response to his hepatitis C disclosure may have contributed to him further internalising the social stigma attached to hepatitis C. This example also reveals some of the social complexities of disclosing (and receiving) a positive hepatitis C status in social network situations.

Sue believed that hepatitis C was 'serious', particularly because of what she believed were the many people affected:

I'd say [hepatitis C is serious] because so many people could be affected. It's really a risk pretty much that's why you always use caution around people ... Yeah it [hepatitis C] is serious to me but I don't know about the other people. [It's serious] because I don't really want to have a disease in my body for the rest of my life when you know that it couldn't probably be treated type of thing, when you know it's always going to be there. But you know that you've already had it and then it's just like 'oh I don't want it again'; you get really paranoid ... Yeah, like [hepatitis C] can really change you. Yeah, it's like your body has all this contaminated stuff well that's what I would think (Sue, F16).

For Sue, her belief in the seriousness of hepatitis C meant she was careful to reduce the risk of acquiring this infection, including by not injecting with anyone that she believed was hepatitis C positive. A particularly interesting aspect of this quote is Sue's use of the term 'contaminated' to explain what she thinks people must feel like if they acquire hepatitis C. Sue also implies a belief that there is no cure for hepatitis C, which was also voiced by her boyfriend Tim. However, in Sue's case, this was expressed as there being no hepatitis C treatment available.

Chris also viewed hepatitis C as serious because of what he believed to be the ubiquitous nature of the virus within PWID populations:

Oh I used to speak about [hepatitis C] all the time because down in Sydney, when I was living on the streets down there heaps of people had hep C and we'd always say to each other you know, 'we're not gonna wind up with it'. People who think they won't come into contact with [hepatitis C] are just trying to fool themselves because they will always either come into contact with someone who has it or they will end up getting it. As I keep saying to everyone, 'don't listen to me until it's too late' (Chris, M21).

For Chris, the seriousness of hepatitis C was exacerbated by what he believed were unrealistic expectations of some PWID, including his friends, regarding their potential risk of coming into contact with hepatitis C. Chris describes himself as having once been in a kind of denial, but as having since developed the ability to understand that he and his networks had been ‘fooling themselves’. This example also highlights the importance of networks in determining what kinds of conversations about hepatitis C are, and are not, socially accommodated and able to be discussed.

Tim was the only Newcastle network member who did not position, or describe, hepatitis C as serious or a priority to avoid. Tim explained: “I dunno anyone that’s got it so [it’s not a priority]”. This positioning was directly related to his belief that he knew no-one that was hepatitis C positive, and possibly also to his general lack of knowledge about hepatitis C. Most importantly, this perception was directly influenced by Brad’s non-disclosure to Tim about his positive hepatitis C status. Although it is not clear why Brad chose to disclose to Chris and not to Tim, this non-disclosure had clear implications for Tim since he believed incorrectly that he knew no-one with hepatitis C. Surprisingly, the belief that there was no cure for hepatitis C, identified by Tim earlier in the chapter, was not incorporated into his perception regarding the seriousness of hepatitis C.

4.3 Hepatitis C-related communication

The following section will explore reported instances of hepatitis-C related communication, including general conversations and disclosure of hepatitis C antibody status, which were reported to occur between members of the Newcastle network. As there was very little network-based communication about hepatitis C evident within the Newcastle network, this section will explore hepatitis C-related communication through the theme of absence. This absence appeared to be a reaction to some extreme and violent responses that had occurred within the network as a result of initiating hepatitis C-related conversations in the past, and a perception that there was no need to engage in hepatitis C-related discussions until or unless PWID knew they were hepatitis C positive.

Additionally, as there was an absence of hepatitis C status disclosure reported within the Newcastle network, this analysis will also discuss an observed practice of inferring hepatitis C antibody status on other network members that was seen to take place due to the absence of disclosure discussions.

4.3.1 Absence of hepatitis C discussions

None of the Newcastle network members reported a history of discussing hepatitis C-related matters in their network sub-groups. Chris explained that, from his perspective, he was reluctant to open up such conversations because of the extreme response he had received in the past when he had initiated a hepatitis C-related discussion with his brother:

That's one subject me and my brothers just don't talk about. For some reason it's like voodoo [taboo], we stay the hell away from it. I've brought it up once and we [Chris and John] ended up in a big punch up. I don't know how it got out of hand? I was just sitting there, I was telling me brother about me mate Brad who's got hep C and that he's just found out two days ago or something that he's got hep C and we were talking about it and I dunno why me brother just got really aggro and just snapped. Then I snapped and then next I knew both of us were on the ground with broken arms. It was an all in brawl. No [I haven't initiated a conversation about hepatitis C with my brothers again] (Chris, M21).

For Chris, a violent encounter had occurred as a result of initiating a hepatitis C-related discussion and although Chris did not quite understand why such a reaction had occurred, he seemed to be implying that his brother was deeply uncomfortable with or threatened by the subject. Perhaps his brother was fearful that he had also come into contact with hepatitis C as a result of injecting with Brad, the friend who had disclosed his positive status. Whatever the reason behind his brother's response, the violence that arose as a result of initiating the discussion had ensured that Chris was committed to maintaining that silence.

Jayde also spoke about how hepatitis C-related conversations were not generally discussed within her network sub-group:

Once [I had a conversation with my friends about hepatitis C] and then we really quickly got off the subject. It was really awful. Yes [it did scare me] that they brought it [hepatitis C] up. We never talk about that, never ever, ever and I don't know why they brought it up but we spent about five minutes or less on it then we just changed the subject. It kind of scared me and surprised me in a way that like after all this time we sat down and like freely talked about it. I thought like 'what's going on here'? You know there's been times I've thought about something and then thought 'oh no I can't talk about that here'. You know because you just don't know how the other people are going to react. You know because you just don't know who's got hep C and if they've got it then they don't like themselves for it. You might make them feel really bad talking about it and then they'd feel really singled out about it. That's why I don't really talk about [hepatitis C], you just don't know (Jayde, F16).

The experience of having a discussion about hepatitis C initiated by friends was seen as surprising and frightening for Jayde because she knew that hepatitis C-related conversations were viewed as unacceptable within her network. She suggested that people felt particularly uncomfortable discussing hepatitis C because of the possibility that others in the network might be hepatitis C positive and could feel 'singled out'. Jayde also identified an instance in which she wanted to talk about hepatitis C with her friends but was unable to do so as she perceived this topic of discussion to be unacceptable. Jayde's description of this conversation as profoundly memorable provides further evidence of just how limited were hepatitis C-related conversations among this group.

Jayde also described a conversation that was initiated by her sister, April, in an attempt to gain information about hepatitis C from Jayde:

Yeah one time and April, I don't think she was that confident in talking about [hepatitis C]. [The initial conversation was] very short and sweet but she ended up calling me up a month later and told me she wanted to know a few more things about it. She told me like after me telling her a couple of things about it before she dropped the conversation. She didn't know a couple of things about so she got to learn a couple of things. She didn't know about like blood (Jayde, F16).

Jayde explained that April did not talk about hepatitis C because she did not feel confident in doing so. In this example, the conversation was represented as very short and containing no specific information about hepatitis C. However, upon later questioning, Jayde became aware that April may not have known that hepatitis C was transmitted through blood. Although this is an example where a conversation had been initiated, April's lack of confidence in initiating hepatitis C-related discussions seems to have been compounded by Jayde's reluctance to discuss hepatitis C, noted previously.

As a direct result of the absence of hepatitis C-related discussions occurring between the Newcastle network members, and probably compounded by their lack of engagement with services, network members identified overhearing conversations of other PWID as a key information source for them in understanding hepatitis C. As Chris explained:

I have heard of one thing actually. I was sitting [inside a Newcastle medical facility] and I was listening to two blokes talk about hep C and one of them said that apparently you can get hep C like if one person cuts their finger and like the blood drops on the ground and another person comes along and like slips in it or something, and then they touch something like an open cut or something apparently you can get it that way, but I thought that's a load of shit. So is it possible? I just thought it was a load of shit. That's what I mean like the bloke said like if you got a cut and you touched a lounge or something then someone else had

already used comes down and sits down and touches the same spot, and then touches, like rubs the hole (Chris, M21).

Chris seemed to find this overheard information particularly meaningful; however, this meant that Chris had not been able to check the accuracy of the information he had overheard due to the pervasive silence surrounding hepatitis C within the Newcastle network. Furthermore, the information that Chris had overheard was included in his account of hepatitis C knowledge even though he had questioned its accuracy when relaying the discussion during the interview. What is interesting here is that he had not checked the accuracy of the information he had overheard with staff at the youth service, with whom Chris has a strong relationship. Reliance on information that was overheard was also noted in Tim's understanding of hepatitis C treatment. Tim explained that "Yeah it does [worry me about hepatitis C] because I heard [when waiting in a health service] there was no cure for it". As previously discussed in the knowledge section, Tim's account included the belief that there was no cure for hepatitis C and this was the result of him not believing that he could afford what he believed a treatment regime would cost. Both of these examples demonstrate how a reliance on second hand information – overhearing the conversations of others – is highly problematic, especially when people are unable to check the facts presented in these conversations or where there was lack of knowledge by which to judge the accuracy of the information.

4.3.2 Absence of hepatitis C antibody disclosure discussions

Within the Newcastle network membership, all interviewed participants self-reported a negative hepatitis C sero-status, although one network member who was not interviewed (Brad) was reported to be hepatitis C positive. Within the Newcastle network, it was reportedly uncommon to initiate or discuss hepatitis C antibody status with others. Jayde explained that the reluctance to initiate these types of discussions among her network sub-group was due to embarrassment, especially when being asked about one's own hepatitis C status:

I find it embarrassing to talk about hep C. I'd find it embarrassing if someone came up to me and said 'hey good looking, you got hep C'? Nobody really asks that you know because it's just something you don't do. You keep off those subjects for everything. You just take it and have a good time. No questions asked and you just keep your fingers crossed that no one has any viruses. I think it's because we think we're all macho macho men walkin' around you know what I mean and we can't be beaten and we can't get sick (Jayde, F16).

In the above quote, embarrassment was identified as the main reason that Jayde would not ask others about their hepatitis C antibody status, and did not want to be asked hers. Jayde understood that the lack of discussion about hepatitis C, including disclosure, resulted in a level of optimism that was based on what she described as having your "fingers crossed" regarding coming into contact with blood-borne viruses, such as hepatitis C. However, Jayde built on this notion of taking known risks by also representing herself and her friends as building themselves up as invulnerable, presenting as "macho" and as not being able to be "beaten" by viruses such as hepatitis C.

There was also an absence of hepatitis C antibody status discussions reported by Tim, however, Tim's explanation for the absence of these types of discussions was that he did not believe he or anyone else in his network needed to engage in these discussions:

No, it's just that I don't know anyone that's got it. So I don't really see the need to talk about it. Um true yeah I got no idea [how I would know if anyone was hepatitis C positive] ... I might [want to have a conversation about hepatitis C] if I thought I might have Hep C (Tim, M17).

Tim felt that he did not need to engage with discussions about hepatitis C and believed there was no need to do so until he or someone he knew was hepatitis C positive. This perception somewhat aligns with Chris's notion of not listening to the advice about hepatitis C "until it's too late". When Tim was questioned about how he would know if anyone was hepatitis C antibody positive, he

admitted that he would not know. Interestingly, however, his next statement was that he would only want to talk about hepatitis C if he had contracted it, suggesting that even though he had a generalised belief that he knew no-one affected, he also recognised that he was potentially at risk. This suggests a deliberate lack of engagement in hepatitis C-related discussions which then further reduced the opportunity for Tim to come into contact with any hepatitis C-related information. The belief that there was no need to engage, or discuss, hepatitis C with others was also voiced by Sue, Tim's girlfriend.

All of the Newcastle network members who were interviewed for this study self-reported as hepatitis C negative and all, except Sue and Tim, had not discussed this with others. Network members therefore proposed that discussions regarding hepatitis C antibody status were not perceived as relevant. However, there were instances where other PWID, who did not participate in this study, had previously disclosed a hepatitis C positive antibody status to members of the Newcastle network. Therefore this section will report on the disclosure discussions reported to have occurred between Sue and Tim, and between the Newcastle network members and other PWID, whilst also commenting on the pervasive silence that appeared to surround disclosure in this network setting.

Sue described how, in her experience, discussions about hepatitis C antibody status will typically occur at the beginning of a sexual relationship but were then not be discussed again:

I've talked about hep C with Tim because we were talking about like do you have hep C and [he goes] 'no', and it's like 'do you have chlamydia?' Like [I say] 'no, do you?' and he goes like 'no'. It was actually a really easy conversation to have because we wanted to know about each other, like everything and if we had any of the diseases we would both get checked for that together. Well we only like asked about it [hepatitis C] and then we went like we need to go and get checked up and

that was the end of the discussion. Yeah because Tim caught chlamydia off one of his ex-girlfriends and he thought he still had it so I went 'oh what the fuck'. We don't really talk about it but we had an argument over it and I'm like 'go and get bloody checked out' so he says 'what's the point I think I've still got [chlamydia] and I'm going 'if you've still got it then you'll give it to me and I'll be fuckin' pissed at you' (Sue, F16).

Similar to that reported in the South-East and South-West Sydney networks, in chapters 5 and 6, the disclosure of hepatitis C antibody status was more likely to occur between people in intimate relationships. Within the Newcastle network, Sue and Tim discussed their hepatitis C antibody status with each other at the beginning of a relationship, which involved asking, and subsequent disclosure, of hepatitis C or sexually transmissible infections. Sue explained how the conversation she had with Tim about hepatitis C had been short and 'easy' because both had disclosed a negative status. In contrast, the discussion about chlamydia was met with a different response because Tim had disclosed that he had caught chlamydia from his former girlfriend and had not been treated. This information resulted in Sue becoming angry with Tim because he was seen to put her at risk of acquiring chlamydia. Sue's negative response to Tim's disclosure of chlamydia suggests that any future disclosure of hepatitis C transmission could be threatening to the relationship. Also interesting here is the different priorities that these network members stressed in relation to different sexually transmitted infections and diseases. For example, Chris viewed hepatitis C as comparable syphilis, which he suggested was not to be feared, whereas in the above example Sue's fear of chlamydia transmission was indeed evident.

Chris and Jayde recalled some discussions about hepatitis C antibody disclosure that had occurred within their respective network sub-groups in the past. For Chris, this was explained in terms of the disclosure from Brad, which has previously been discussed:

Well my mate's got hep C right. He didn't have it when I first met him. He never had it and I told him not to share needles, not to use someone else after they'd used it but he didn't listen to me. He used another bloke's [needle and syringe] that he'd just met and went in for a regular blood test and came up positive. I said to him 'I told you not to share' and he's gone 'oh well I was hanging for the buzz' and I said 'see what the buzz gets ya'. Yeah, we're still good mates, like best mates, he comes down to my place once a week to shout me or up at his place have coffee and cones. We would have spoken about it a couple of times [since]. I just talk about like if they come up with a treatment (Chris, M21).

This extract highlights how more subtle levels of judgement can become part of a person's response to hepatitis C disclosure, as had happened in this example when Chris had informed Brad prior to testing positive not to share injecting equipment. Although Chris explained that this disclosure did not affect his social and injecting relationships with Brad, the 'I told you so' type of judgement enacted by Chris may have influenced Brad's future willingness to disclose to others, including not disclosing his status to Tim or Sue. Furthermore, while this disclosure provided an avenue for Brad and Chris to discuss hepatitis C treatment, no detail related to these discussions was recalled, nor was there any evidence that issues related to hepatitis C transmission were discussed between the two. Chris's response was quite revealing, in fact, of the lack of language or capacity that this Newcastle network appeared to hold regarding how to discuss hepatitis C or respond to the disclosure of hepatitis C infection by others.

Although discussing hepatitis C antibody status was rare, some members of the Newcastle network inferred a *negative* hepatitis C antibody status on other network members, even where a discussion on status had not taken place. Jayde was the only member of the Newcastle network who did not infer a negative hepatitis C antibody status on others and she explained this as not asking and therefore not knowing. There are significant implications of this practice of deliberately assuming

negative status of other members of your injecting network, which appear to be compounded by a fear of raising the issue for discussion.

4.4 Social network dynamics in the injecting environment

The following section will explore the social network dynamics that shaped injecting practices within this network. This will include an analysis of the practices and rules that were seen to be typical of injecting settings, including network structure, injecting hierarchies, injecting practices, ritualised use of injecting equipment and the transmission risk of other non-injecting based practices. This section will also consider some ways of thinking about why these social network dynamics may have occurred in this fashion and how they may have positively or negatively influenced hepatitis C transmission risk.

4.4.1 Network breakdown

As a result of the sexual affair between Chris and Sue, and the subsequent breakdown in relationships between Chris, Sue and Tim, network membership of the new sub-groups had become closed and this directly influenced the risk of hepatitis C transmission within the sub-groups. For Chris, participation in an injecting episode was based on a closed group membership that only included his brothers and Brad. This closed membership would not only influence transmission risk for Chris, it also reduced the potential for new knowledge on preventing transmission to reach this group of PWID. For example, Chris explained that he was particularly reliant on Brad for hepatitis C-related information:

Oh my health info I usually get from Brad. I wouldn't have a clue [where he gets his information from]. [I would go to] Brad, me mate, because of the fact that he's positive but he'd know more about it than me. Like doctors would have to give him like some information pamphlets about it (Chris, M21).

Chris believed that Brad's positive hepatitis C status would result in Brad being more knowledgeable about hepatitis C because of his increased access to doctors, who Chris assumed would provide Brad with information. This reliance was also impacted by the existing lack of knowledge of his sub-group members. For example, as Chris was not aware that spoons were a possible hepatitis C transmission risk, any assessment of risk with respect to Brad's positive hepatitis C status may have been ineffective in any instance where the spoon was shared.

The sub-group that Tim, Sue and Brad were members of was also closed. Brad controlled the group's membership and therefore Tim or Sue would not be permitted to bring people with them when they injected. Tim explained that if he was to bring someone new into the injecting episode they would "probably get punched out the door. Like anyone that he [Brad] knows is OK". For Tim and Sue, the closed nature of the sub-group served to increase their risk of acquiring hepatitis C transmission. Since we know from other interviews that Brad had previously disclosed his hepatitis C positive status to Chris, this disclosure had not occurred between Brad, Sue and Tim and therefore any decisions made about injecting practice and risk were based on this assumption. Given that Brad was in control of providing sterile injecting equipment, preparing the drugs and injecting Tim and Sue, a number of different transmission risks could be seen to occur. These factors were also compounded by the injecting hierarchy, discussed by Tim and Sue below.

4.4.2 Injecting hierarchy

Injecting hierarchies were evident within the network members' accounts of injecting practice; however, this was not typically identified as increasing the risk of hepatitis C transmission among the Newcastle network. Sue identified a complex interplay of factors within this sub-group that she believed resulted in an injecting hierarchy that was completely outside her control:

Brad, he doesn't [just] mix the drugs he actually goes out and gets it for us because
[the Newcastle suburb where the drugs are purchased] is actually a bad place kind

of thing. You can get rolled quite easily, if you keep your head down you're right but you could quite easily get rolled ... Brad he gets them [sterile injecting equipment from the chemist]. Pretty much he prepared it for us. I watch it [Brad preparing the drugs] with the heroin but with the morphine I've already seen it. I used to [prepare the drugs] but I usually sit back and let somebody else do it now ... I can't find my vein anymore. I can get butchered [ending up in] track marks. Yeah Tim he usually does it [injects me] all the time now (Sue, F16).

For Sue, the injecting hierarchy was not only influenced by the power dynamics of each injecting episode, but also by other issues related to sourcing both drugs and injecting equipment. Sue explained that she was unable to access the dealer in her area because of an inability to 'blend-in', thus increasing her reliance on Brad. Blending in required people to look as though they belonged in that space, which was made difficult for Sue because she was young and had a 'surfer' look, compared with those who lived in the area and who may have been older and identified with more of a street-based sub-culture. Using Brad to access these areas reduced the risk of violence towards Sue; however, it also located control regarding the subsequent injecting episode with Brad. Sue was also reliant on Brad to access sterile injecting equipment, as a result of her negative experiences when trying to purchase sterile injecting equipment. Within an injecting episode, Brad was also responsible for preparing the drugs and then injecting Tim. Sue explained that she did not pay attention to the drug preparation process as she did not believe there was a need to do so. This lack of attention during drug preparation processes means Sue is very unlikely to be able to assess and reduce the risk of acquiring hepatitis C. Lastly, Sue's inability to inject herself due to vein damage also positioned her as last in an injecting episode. Although Sue identified these factors in her accounts of injecting, she did not consciously acknowledge or understand that these factors placed her at increased risk of hepatitis C.

In contrast, Tim's account of injecting with Brad and Sue rejected the notion of an injecting hierarchy and the practices that occurred in this group were seen to be based more on convenience:

Um no [there is no injection hierarchy] really just whoever goes gets [my drugs] for me and because I know the bloke I can go myself and that it's just convenience.

Yeah and if he's got like if there's 30 ml in one needle and 20 ml in the other he'll give me the 30 ml (Tim, M17).

In this account, Tim positions himself as having equal status to Brad, with no particular order expected when injecting together. Sue was not included in this account, which may have been because she was positioned last in the injecting hierarchy when all three were present, perhaps revealing an implicit assumption about gender roles. Tim also observed a rule regarding not injecting alone, which he explained in terms of overdose risk management, which he believed that neither himself or Sue could adequately manage or respond to. As Tim explained, "I just don't use by myself because if I drop well there's no one around".

Jayde expressed the most explicit accounts of the potential for control to be enacted in an injecting episode, including the observation that if you are not responsible for drug preparation, you have a reduced capacity to recognise risks to safety:

Oh well, half the time we do it somewhere else but when it's at my house it's like well I'm in the driver's seat so get out. Yeah and when we're at her [sister's] house it's like she's the big show. She runs the show ... My sister [usually prepares the drugs]. I dunno because she thinks she owns the place. Yeah, she's just like, she's the one who always walks in and she just goes oh alright go ahead and no it's like it's my turn to start up. Yeah [I watch her when] she starts [preparing the drugs] and half the time I'll look away. We don't really look at each other while it's all happening. It makes you nervous when you've got someone staring at you like. Yeah but half the time I am but I don't take that much notice of it. I just take notice

of when I'm sober beforehand just so I double check everything and I know what I'm doing, I don't do it when I come home half pissed (Jayde, F17).

Jayde was clearly aware of how the specific injecting setting increased or decreased her ability to be in control. She also identified how this could result in the establishment of a particular injecting hierarchy, which was determined by whose home she and her sister were injecting in. Control of the drug preparation process created tensions because Jayde believed that April always tried to control this. It was not clear whether Jayde had challenged this practice or how her sister would react if she had done so. Additionally, Jayde also described how embarrassment could influence vigilance in an injecting setting. She explained this embarrassment in terms of being watched when preparing drugs, which led to the practice of not consciously watching others prepare drugs. Jayde also recognised how drinking alcohol could impair her ability to be vigilant in an injecting episode; however, she did not describe any instances of this actually occurring.

4.4.3 Injecting equipment practices

There was a different level of concern attached to the reuse of injecting equipment depending on whether the individual was reusing their own equipment, or sharing equipment previously used by others: the latter was considered more risky. However, the sharing of other injecting equipment, such as spoons, did not appear to be viewed as being as serious as that of sharing needles and syringes and accounts of episodes in which there was some reuse or sharing of injecting equipment was typically explained in terms of the demands of particular circumstances.

Although Chris recounted experiences of having to reuse his own injecting equipment, he stressed that he would never share or reuse other equipment belonging to other PWID:

I've had to re-use [my own] fits heaps of times but I won't use anyone else's, like I'm very paranoid about that. I'll re-use me own but no one else's. [My mates] not as much as me, they don't really care that much. They just want the high, that's it.

They don't care how they get it or how they get it just as long as they get it. Oh I've said like things to them about using and cleaning and they're just like 'oh fuck man I just want the buzz' so that's their preference (Chris, M21).

Chris explained that the reuse of one's own injecting equipment was not believed to be as risky as reusing or sharing another person's injecting equipment. Reusing one's own injecting equipment was seen to be the result of circumstance, whereas, reusing another person's equipment was the result of not being vigilant enough, or not caring about one's health. The above example also highlighted that when there was insufficient information regarding hepatitis C transmission risk in the network, unintended sharing, such as the sharing and reuse of spoons, could occur and not be understood to be a transmission risk.

Like Chris, Sue explained that she would never share other people's injecting equipment:

Never [shared or reused injecting equipment]. Actually I've never shared any because I know what it does to you. It can change, like you can get hep C from cross blood infections and all that kind of stuff and I don't want that shit. Even if I am on a binge, I know right from wrong. Anyway I'm not that stupid. I usually have my drugs first before I drink (Sue, F16).

Sue explained that her decision never to share other people's injecting equipment was the result of being scared of hepatitis C, including the ability to come into contact with a number of different hepatitis C strains. Sue also believed that the sharing and reuse of other PWID injecting equipment was both wrong and 'stupid', and she seemed keen to distance herself from these judgements. Within this explanation, Sue also suggested that her vigilance could be impacted if she were to drink alcohol prior to injecting, however, she stressed that she would always inject before drinking and therefore alcohol would be unlikely to impact injecting practice.

Jayde described situations where she had become aware of other young PWID breaking into disposal boxes for injecting equipment located in public toilets to obtain needles and syringes:

Yeah it's disgusting because like you think about it. [They may not think about] how it can actually affect them later on and like you'll see it, if you sat there in the toilets you'd see it happen four to five times in one day. They'd go in and break open them sharps box, or unpick the locks, take all the used [needles and syringes] out and if there is something worth leaving in there, they'll friggin, they'll just shoot that up straight away ... It could be you know because they think they'll get shunned on or they think they're not worth it or you know it could be a million things to them. Like every person's excuse to their own. Half the time I think it's just like feeling shameful going in [to a service] and asking for something [injecting equipment]. It's harder to do that than to like you know. It's hard to come in for something sometimes like I used to be, than ask for a fit pack than to just get something out of a box elsewhere where no one's gonna see ya (Jayde, F16).

The example provided by Jayde above, of young people breaking into sharp disposal boxes in public toilets to obtain needles and syringes, is alarming if this is an accurate observation. Initially Jayde explained the practice in terms of PWID being able to use whatever drug solution was left in the needle and syringe. However, Jayde then explained that the practice, especially for young PWID, may be the result of shame acting as a barrier to accessing injecting equipment from services because they may be seen doing so by others. This practice also highlighted the lengths, and risks, that PWID may go to access injecting equipment without being seen.

Tim explained that he had reused another person's injecting equipment that was kept in a drawer after use: "Oh I have used someone's [needle and syringe] once. I just couldn't find a fit [needle and syringe] and I looked in his drawer and he had one and I said 'could I use that' and he goes 'yeah' and I just used it". Tim's explanation of the reuse of another's injecting equipment was a result of

not having access to sterile injecting equipment when required. Additionally, as the example was referring to the reuse of Brad's needle and syringe, this would increase the risk of hepatitis C transmission as it had been previously reported that Brad was hepatitis C positive.

Chris also explained how injecting equipment, in this instance the 'lucky spoon', had been reused and shared because it had become symbolic and ritualised within an injecting episode:

Yeah I got me lucky spoon. Yeah I've had it for years. I dunno, one day I was there mixing up and everything with the spoon and the coppers just walked into the squat and busted me [preparing the drugs]. I had a couple of points on me, my brother was sitting next to me and he had full weight on him [but] they didn't bust us? They didn't worry about us, they just opened the door, gone oh yeah, shut it and walked off (Chris, M21).

For Chris, the reuse of his 'lucky spoon' was not acknowledged as a risk practice because Chris was unaware that spoons were a transmission risk for hepatitis C. However, Chris's example goes further than only identifying how pieces of equipment can become ritualised in the injecting environment by also highlighting how this can change if PWID are given access to new information. This was evidenced when Chris was told after the interview about the hepatitis C transmission risk from spoons and he immediately declared that he would "be chuckin' the lucky spoon out today!"

A practice of sharing and reusing injecting equipment, called 'passing the jockey', was also described by Jayde:

Passing the jockey is where basically you take half a hit, and the next person takes half and you just keep going around until it's refill, refill, keep going around if you're left with one [needle and syringe]. Say you got left with one in the drawer, or one wherever you keep it, you just use the same fit [needle and syringe]. Yeah [it's common practice]. When I was growing up it was because none of us had balls to

go into a place like this [NSP] because we thought if [staff] found out we're dead meat and they'd tell our parents and that's something we just didn't want to happen (Jayde, F16).

Passing the jockey was a practice of high risk for hepatitis C transmission that involved the sharing of one needle and syringe amongst a group of friends. The practice basically seemed to comprise filling the syringe and passing it around a group until there was no drug solution left. Whoever received the last part of the drug solution got to keep the needle and syringe for reuse at a later time. Alarming, this practice was so common that it had received a name amongst Jayde and her friends. Participating in such a high risk injecting practice appeared to be the direct result of both not understanding the risks of hepatitis C transmission and not wanting to access sterile needles and syringes from services. Given the young age of Jayde and her friends, preventing family, including parents, from becoming aware of drug use may also be significant when trying to hide drug use from others.

Jayde explained that she did not understand the risk of passing the jockey until her teacher had informed them about hepatitis C:

Oh my teacher was standing out the front and she was giving out these pamphlets about it [hepatitis C] and saying that how risky it was, for young people to be like even if you hurt yourself or touch the blood of another person. How risky that can be for hep C or using the same [injecting equipment], using with your friends, you know play pass the jockey around. I never realised how bad it was until I actually listened to that and it was probably the first words I had actually listened to (Jayde, F16).

Since Jayde's exposure to information about hepatitis C and transmission, she claimed that she no longer participated in passing the jockey. This example suggests that even the most basic of

information about hepatitis C transmission risks, such as the sharing of needles and syringes in an injecting episode, can have powerful affects when it reaches networks of young PWID.

4.4.4 Image management and blending in

As previously described, Sue explained how the inability to ‘blend in’, within the area in which she sourced her drugs, prevented her from purchasing drugs on her own and subsequently contributed to constructing a hierarchy of injecting. However, blending in was also described by Jayde in terms of being able to hide the injecting marks on her arms:

Yeah it does [worry me about having track marks from injecting] because people look at you like you’re really disgusting. It makes you feel guilty, you know what I mean. Well it’s just like you’d be sitting on a bus right and you’d be getting off at a stop or something and you stretch your arm out to press the button and someone will see like where you’ve just had your wake up morning coffee and see this huge big bruise from a couple of times that you’ve hit the same one [spot]. They just look at you like you’re a piece of shit or something and it just makes you want to get off that bus as fast as you can and run. Yeah, it’s basically judgment (Jayde, F16).

In the above extract, Jayde described negative societal constructions of drug use and how judgement from the general public, especially in those judgements passed in everyday situations such as catching a bus, had been internalised. Importantly, this example highlights how issues of shame and guilt among young PWID as a result of their injecting drug use could provide further validation that it is not safe to articulate a need for services or information related to injecting.

4.4.5 Self-harming as a hepatitis C transmission route

The risk of hepatitis C transmission was not restricted to the sharing or reuse of injecting equipment. Jayde explained how other practices, such as self-harming, also posed a risk for hepatitis C transmission:

My girlfriend, she was a self-harmer, I was a self-harmer. We used to use the same [razor] blade, you don't think like, back in those days, you don't really think of yeah like this blade has got my blood mixed with hers kind of thing. You don't really think outside the box with hep C, like how it can actually, how you can be affected by it or that person can be affected by it. You're not thinking about it like if you're using the same blade as another person. It's still blood on the blade and it's mixing with theirs and that (Jayde, F16).

The practice of cutting involved the use of razor blades to self-inflect cuts on the skin, which is a practice that normally draws blood. Jayde explained how she and her ex-girlfriend were cutting with the same razor blade and now realised that this activity posed a serious hepatitis C transmission risk that was not realised at that time. Jayde believed she and her ex-girlfriend had avoided 'thinking outside of the box' in relation to their self-harming practices, and had therefore not conceptually linked the risk of hepatitis C to practices other than injecting. Jayde's notion of 'not thinking' highlighted how study participants' accounts of hepatitis C transmission tended to focus on general accounts of the sharing and reuse of needles and syringes: while other non-injecting activities, such as self-harming, and other injecting equipment, such as spoons, which would pose the same risk, were not considered to be as harmful.

4.5 Summary of the Newcastle network

Although the Newcastle network members were quite young, they had been injecting for at least three years prior to interview. However, it was only in the year or two prior to interview that members had come into contact with basic information about hepatitis C transmission risks, such as the sharing of used needles and syringes. The transmission risk of other injecting equipment was only recently known to some and not at all for others. Interestingly, Chris also identified that he believed that hepatitis A, B and C were the same virus, a finding also reported in studies conducted with other groups of PWID (Rhodes et al., 2004) as well as among the general community (Hopwood,

Brener, & Wilson, 2012). The network also showed how new knowledge entering the network could change injecting behaviour, including the reuse of spoons and participation in group needle and syringe sharing.

Most Newcastle network members believed that hepatitis C was a serious concern, although it was common to view HIV as a greater concern than hepatitis C. Others believed that hepatitis C was serious, although this was not translated into behaviour change because they did not believe they were injecting with anyone that was hepatitis C positive. Of particular concern were the reports from Tim that suggested he believed he did not need to engage with hepatitis C-related education, including initiating any discussions about hepatitis C with other network members, because he was not hepatitis C positive. In fact, there was a general absence of hepatitis C-related conversations occurring between Newcastle network members. Initiating these conversations in the past had been met with violent responses, for some, which demonstrated that these discussions were viewed as unacceptable. Where discussions did occur, they typically involved one-off disclosures about status or short conversations about hepatitis C being a blood-borne-virus, and often within sexual partnerships. The impact of this absence of discussion resulted in some of the network members relying on overheard conversations as sources of information about hepatitis C risk and prevention, despite this information not being able to be validated.

The Newcastle members reported social network dynamics that directly impacted on the level of hepatitis C transmission risk they were exposed to, and in most cases this risk was not explicitly recognised. For example, the need to hide drug use and the role of shame in discouraging access to services could also be seen to at least partly explain the very high risk practices described of sharing and reuse of equipment, including breaking into sharps bins and sharing one needle and syringe in a group setting. The accounts of the Newcastle network members also highlighted how the risk of hepatitis C transmission occurs beyond a specific injection episode, with risk also seen to be

influenced by the setting and the current and historical relationships between the people present (or excluded) from specific injecting episodes. By focusing on factors beyond the injecting episode, accounts from members of the Newcastle network suggested that a lack of control of factors related to sourcing, preparing and injecting drugs as well as accessing injecting equipment, all contributed to hepatitis C transmission risk. The Newcastle network also highlighted the fluid nature of social networks and showed how the breakdown of network relationships could be as important as the current injecting-based relationships with respect to hepatitis C transmission risk. This was because the network and relationship breakdowns resulted in the need to form new relationships, which involved negotiating new and different mechanisms of order and authority.

The next chapter will report on the research conducted with a network of PWID residing in the quite different geographic and cultural environment of South-West Sydney. The structure of the forthcoming chapter will reflect that contained in this chapter, exploring hepatitis C-related understandings, communication and network dynamics, with an interest in the commonalities and differences evident in the particular social conditions of South-West Sydney.

Chapter 5 South-West Sydney network

5.1 Study site overview

5.1.1 The setting

The South-West Sydney study site is a large geographic area comprised of a number of residential suburbs and suburban business centres, located approximately 50km south-west of Sydney's central business district. The South-West Sydney area has a large number of migrant residents: approximately 40% of individuals living in the area were born outside of Australia and 70% of households speak a language other than English at home (Australian Bureau of Statistics, 2011c). Within South-West Sydney, there is a particular concentration of people from South-East Asian descent, including those from Vietnamese, Cambodian (Khmer) and Laotian backgrounds (Australian Bureau of Statistics, 2011c).

Extensive research has been conducted with PWID of South-East Asian descent in Australia, including those residing in South-West Sydney. Results from these studies suggest that PWID from South-East Asian backgrounds do not make regular use of needle and syringe programs (Coupland, Maher, & Ritchie, 2004; Le, 1997; Louie, Krouskos, Gonzalez, & Crofts, 1998; Maher et al., 1997) and have little contact with general health services, except in emergencies (Higgs, Nguyen, Ezard, & Crofts, 1999; Louie et al., 1998; Swift, Maher, & Sunjic, 1999). It has also been reported that Vietnamese PWID in Australia have a high prevalence of hepatitis C and limited awareness of blood-borne virus (BBV) transmission (Hellard et al., 2006; Hellard, Nguyen, Higgs, Guy, & Mijch, 2005; Kelsall, Higgs, Lam, & Crofts, 1998; Louie et al., 1998; Maher, Chant, Jalaludin, & Sargent, 2004; Maher et al., 2001). Compounding a high prevalence of HCV, PWID from South-East Asian backgrounds are less likely to have been tested for hepatitis C but more likely to test positive for hepatitis C antibodies (Kelsall et al., 1998; Louie et al., 1998; Maher et al., 2004; Maher et al., 2001).

Drug use in the South-West Sydney area has received considerable public and policy attention over the last couple of decades. In the 1990's and 2000's, the study site area was described as the 'heroin capital of Australia' (Topp, Day, & Degenhardt, 2003) and identified as one of Australia's largest street-based heroin markets (Maher, 2006). Given the size and notoriety of the heroin market in South-West Sydney, a train line that travelled through the area from the Sydney CBD was dubbed the 'smack express' (Warhaft, Black, & Sindicich, 2007). In 2001, the NSW Premier tabled a ministerial statement and policy to combat drug use and street-based heroin supply in the area (Griffith, 2001). This policy was implemented in South-West Sydney through zero tolerance policing of drug supply and use. Although these changes in law enforcement were seen to have some effect in improving quality of life for the general community (Maher & Dixon, 2001), zero tolerance policing also resulted in a number of unintended consequences that directly impacted the health and welfare of PWID in South-West Sydney, including reducing the willingness of PWID to carry sterile injecting equipment (Dixon & Coffin, 1999), a trend towards unsafe storage and transfer of drugs by street-level dealers and increased high risk injection practices (Dixon & Coffin, 1999; Maher & Dixon, 2001; Maher et al., 1997).

Perhaps unsurprisingly, PWID services in the South-West Sydney area have had an interesting history. In 2003, the only NSP in a key suburb, Cabramatta, was ordered to close by the NSW Government because it was suggested that illegal drug deals were taking place outside the service (Totaro & Pollard, 2003; Videnieks, 2003). This incident highlighted the different perspectives surrounding drug services in the South-West Sydney area. For some in the local council, it was believed that "harm minimisation does not work in Cabramatta there is definitely a honeypot effect, the street prostitution and drug deals are all up where the [drug centre] is [*sic*]" (Videnieks, 2003). Conversely, the Executive Director of the NSW Users and AIDS Association (NUAA), NSW peak non-government organisation for PWID, claimed that this service closure was "a prime example of police targeting users and making the environment hostile" (Totaro and Pollard, 2003). Given the tensions

in this local history, services for PWID in South-West Sydney could only be described as inadequate. At the time of data collection, sterile injecting equipment was distributed through only one primary NSP, which serviced a number of adjoining suburbs. The primary NSP also provided an outreach van during non-business hours and a number of pharmacies in South-West Sydney participated in the NSW Pharmacy Fitpack Scheme , whereby PWID could buy or exchange used injecting equipment (NSW Department of Health, 2013b).

5.1.2 Recruitment

The social network recruited in South-West Sydney was the second to take part in this study. Recruitment processes began after discussions with staff of a Sydney-based PWID organisation that identified contacts in the South-West Sydney area. The key individual recruited to the study site has been allocated the pseudonym of 'Dung'. Dung worked in South-East Sydney and was easily contacted as he frequently attended a Sydney-based PWID service. Although Dung participated in the study interview, his interview responses showed minimal social contact with other PWID, especially those in South-West Sydney. Therefore, Dung provided recruitment links to other PWID in South-West Sydney who were identified as acquaintances, rather than friends. These acquaintances had been friends, and had injected with Dung in the past, however, no current social relationships were reported by Dung or other South-West Sydney network members. Dung asked his acquaintances for permission for the researcher to make contact with them. As a result of this contact, Hao and Tai were recruited to the study. When Hao attended the study interview he was accompanied by his girlfriend, Mai, who was also recruited and interviewed immediately after Hao. Tai was interviewed and contacted his friends, Binh and Sarath, who also agreed to participate in the study. Tai accompanied both Binh and Sarath to meet the researcher and these people both subsequently participated in the study interview. Although Sarath and Binh identified other people that they would inject or socialise with, these relationships were not described in any detail. For other South-West Sydney network members no other significant injecting or social relationships

were identified, with the exception of family. However, the inclusion criteria for this study did not include family members unless they formed part of a current injecting network and therefore the influence of family will only be discussed in terms of wider macro-level influences in injecting practice and transmission risk.

5.1.3 The main characters

The South-West Sydney network was comprised of six individuals reported to be socially connected for over ten years. The South-West Sydney network membership consisted of PWID who were all quite young, of South-East Asian descent and had smoked heroin at least five years before transitioning to injecting. Five members of the social network were from Vietnamese backgrounds and one was from a Khmer background. All network members were receiving methadone maintenance at the time of interview and all but one member, Binh, had stable accommodation in their parent's family home. All network members had been incarcerated in the past and described being tested for hepatitis C during those periods. All networks members also spoke of being known to police in their local area due to criminal practices related to their drug use. All network members were receiving social security as their main source of income, except Dung who was in part-time paid employment. Dung was the only network member who had had prior experience of taking part in a research study.

Dung was a 32 year old male of Vietnamese descent who had smoked heroin during his teens and began injecting at 21. Dung left formal education after completing Year 10. He lived in South-West Sydney with his parents and travelled daily to SES to work. At the time of interview, Dung explained that he injected heroin approximately once a week, always at home and by himself. Although there were people Dung reported that he would inject with, he had not done so recently and therefore Dung identified Sarath, Binh, Tai, Mai and Hao as associates in the drug scene, rather than friends or acquaintances. Dung accessed all of his injecting equipment needs from an NSP in South-East

Sydney, rather than one closer to his place of residence. Dung had been incarcerated a number of times, totalling three years, and had injected heroin during his sentences. Dung self-reported as hepatitis C negative.

Sarath was a 28 year old male of Khmer descent. Sarath was born in Vietnam and lived in a Thai refugee camp prior to coming to Australia in the early years of his life. Sarath left formal education after year 10. Sarath started smoking heroin in his teens and began injecting at 21 and at the time of interview he injected heroin daily, although Sarath had also injected methamphetamine, which he described as occurring on 'special occasions'. Sarath was receiving unemployment benefits and lived with his parents. He would commonly inject in public places, such as in stairwells or behind apartment buildings in the South-West Sydney area, although he also reported injecting at home. Sarath accessed his sterile injecting equipment from the only NSP in the area because it was free. Sarath had been incarcerated and injected heroin during his sentence. During this prison sentence he was tested for hepatitis C, and Sarath self-reported as hepatitis C positive.

Tai was a 27 year old male of Vietnamese descent who had smoked heroin in his teens and had started injecting at 24. Tai left formal education in Year 11 and his main source of income was unemployment benefits. At the time of interview, Tai was living with siblings in the South-West Sydney area and had not injected for five months because he had been referred to the NSW Drug Court and as part of the court requirement, Tai had had to detox whilst in remand. Tai was also drug tested twice a week. Prior to entering Drug Court, Tai had injected heroin daily and had also injected cocaine. Tai had injected in public places such as stairwells, toilets, and car parks and accessed sterile injecting equipment from pharmacies in a different suburb from where he lived. Tai had been recently tested for hepatitis C at a methadone clinic and self-reported as hepatitis C positive.

Binh was a 24 year old male of Vietnamese descent who had smoked heroin in his teens. Binh had left formal education after completion of Year 10 and his main source of income was unemployment benefits. At the time of interview, Binh stated that he used heroin daily, always smoked, and therefore did not identify any service where he had accessed injecting equipment or places where he would inject. However, some South-West Sydney network members reported that Binh had injected heroin while others reported that he only smoked it. Binh had been incarcerated and had smoked heroin in prison for the duration of his sentence. At the time of interview, Binh had been recently forced to move out of his parents' home because they had found used injecting equipment in his room, and so he was sleeping on a friend's sofa. Binh was tested for hepatitis C at the methadone clinic and self-reported as hepatitis C negative. As Binh did not report injecting at the time of interview, nor did other network members report on network dynamics including Binh, his inclusion in the South-West Sydney network results will be restricted to reporting his hepatitis C understandings and communication.

Mai was a 24 year old female of Vietnamese descent who had started smoking heroin at 14 and began injecting heroin at 19. Mai left school after completion of Year 10 and her main source of income was unemployment benefits. At the time of interview Mai injected heroin three times a day. Mai was in a sexual relationship with Hao and since the beginning of their relationship two years prior, Mai injected only at home and only with Hao. Mai preferred to access sterile injecting equipment from pharmacies, which she travelled 30 minutes by car to reach. Mai lived with her parents, but was planning to start residing with Hao. Mai had been incarcerated, although she did not smoke or inject illicit drugs during her sentence. Mai had been tested for hepatitis C when she was released from prison two years prior, and although she had not been re-tested, she believed that she was still hepatitis C negative.

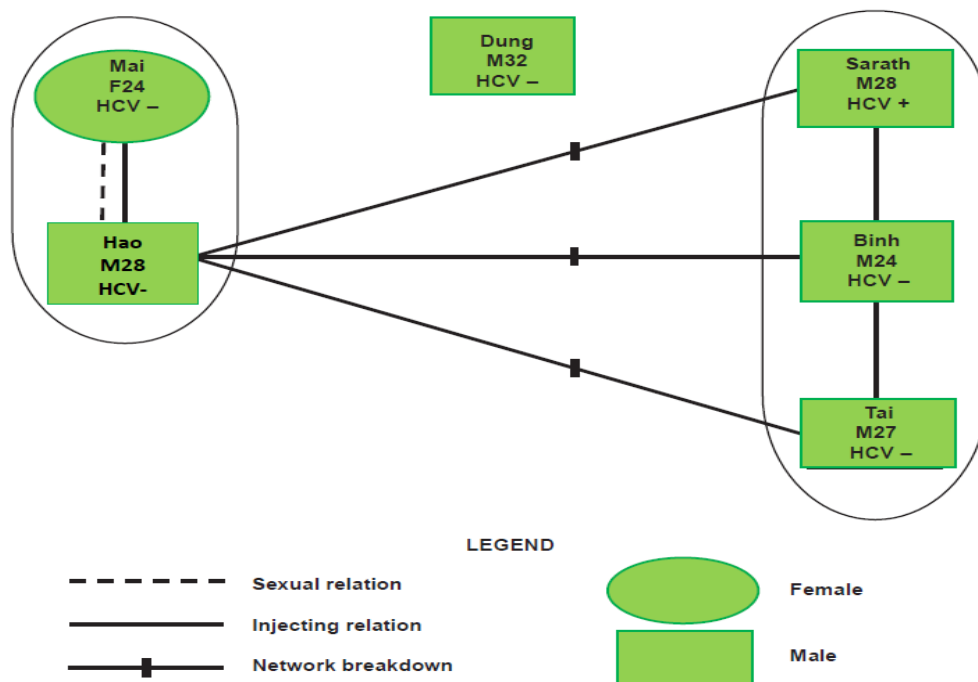
Hao was a 28 year old male of Vietnamese descent who had been smoking heroin since his early teens and had started injecting at 21. Hao left school after completion of Year 10 and his main source of income was unemployment benefits. At the time of interview, Hao injected heroin three times a day, and had been in a relationship with Mai for two years. Hao accessed all his equipment from pharmacies. Hao had recently been granted a public housing apartment and was in the process of moving into this apartment. Prior to entering the relationship with Mai, Hao had also socialised and injected with Tai, Binh and Sarath. Hao had been incarcerated approximately two years prior and during this time he had smoked, rather than injected, heroin. Hao was tested for hepatitis C during this time and like Mai, had not been re-tested since. Hao believed that he was hepatitis C negative.

5.1.4 The network relationships

All members of the South-West Sydney network had known each other for over ten years and there were strong family connections between the different South-West Sydney network members. Due to various custodial sentences and the start of Hao and Mai's relationship two years prior to interview, the South-West Sydney network had formed into three distinct network sub-groups. The first South-West Sydney sub-group included Mai and Hao. Mai and Hao had been in a sexual relationship for the last two years and since the beginning of this relationship injected only with each other. Prior to Hao's custodial sentence, and the start of his relationship with Mai, Hao had been a member of another sub-group that included Sarath, Tai and Binh. This second sub-group was friendship based and was identified as a kin relationship by some of the members because they perceived each other to be brothers. The third sub-group included Dung. Dung had also known the other members of the South-West Sydney network for over ten years. However, in the last few years Dung had chosen not to associate with many PWID from his past except as casual acquaintances, especially PWID from the South-West Sydney area. These broader and hidden networks will be

discussed where appropriate. South-West Sydney social network relationships have been reproduced in Diagram 2.

Diagram 2 South-West Sydney social network and sub-groups



All members of the South-West Sydney network identified kin in their broader social networks. These kin were typically immediate family, including brothers and sisters, some of whom also had a history of injecting drug use. However, these kin were not part of current injecting networks and very little information was reported about these family members by the South-West Sydney network members in an attempt to maintain their privacy. No family members of participants took part in the study. Additionally, Mai and Sarath also identified Anglo-Australian based networks of PWID with whom they had interacted. Sarath injected and socialised with these groups. Mai only identified Anglo-Australian PWID generally, she did not socialise or inject with them. No PWID from Anglo-Australian backgrounds participated in the South-West Sydney component of the study.

5.2 Hepatitis C-related understandings

The following section will describe the South-West Sydney's network members' knowledge and beliefs about hepatitis C and hepatitis C treatment and consider how concordant this knowledge and beliefs was with accepted hepatitis C knowledge. This section will also investigate how these understandings seem to have been developed and shaped, including an exploration of the level of seriousness ascribed to hepatitis C.

5.2.1 Knowledge about hepatitis C

All South-West Sydney network members were aware of hepatitis C and knew it could be transmitted through the sharing and reuse of needles and syringes. Dung, Tai and Hao were able to identify the virus and accepted transmission routes, such as the sharing and reuse of needles and syringes, other injecting preparation equipment and the transmission risk from the injecting environment generally. Tai was the only South-West Sydney network member who spoke about how his hepatitis C knowledge had changed over time. He explained that at the beginning of his injecting career he was not really aware of what hepatitis C was or how it was prevented, other than the need to "[be] more careful". Tai explained this lack of knowledge in terms of psychological issues he had at that time, where "I didn't really care because around then like I'd, like even now I don't really feel like living but like now that I'm off it [the drugs] I feel like more for my family and that". Tai now described his knowledge of hepatitis C in relation to injecting transmission risks and consequences to the body, which he had recently learnt from attending a Hepatitis C Awareness Picnic in his local area:

Just that [hepatitis C] it's inflammation of the liver. [It's transmitted through] blood to blood. Yeah especially like just anything to do with a syringe, the spoon to even filters yeah. I think anything like just say if someone cuts themselves on the wall and you walk past and scratch yourself and it goes deep enough to reach the blood then you can get it that way (Tai, M27).

Tai's account of hepatitis C transmission identified all accepted hepatitis C transmission routes from injecting equipment, with the exception of water. During the debriefing process after the interview I asked Tai if he knew about the risks associated with water and he replied that he was aware of this and did receive water whenever he bought needles and syringes from the pharmacy. Additionally, Tai also identified how the general injecting environment could pose a risk for hepatitis C transmission and although his example of a hepatitis C transmission risk that included scratching yourself on a wall may seem overly concerned, the fact that this level of concern had woven itself into Tai's hepatitis C transmission knowledge could indicate that he may be deliberate conscious of the risk of blood borne virus transmission more generally in the injecting environment. This level of awareness was not apparent among other members of the South-West Sydney network.

Hao explained his hepatitis C knowledge in terms of the primary organ it affected and the various types of hepatitis C, known as genotypes: "Oh [hepatitis C] it's a liver disease. It's a virus and there's heaps of genotypes. I learned that from pamphlets [from] drug and alcohol at jail". Hao was aware of most of the hepatitis C transmissions risks from injecting equipment. However, in the debriefing discussion after the interview it became apparent that he may have underestimated the hepatitis C transmission risk from other injecting equipment, such as filters and water used in the drug preparation process. Hao's observation that hepatitis C included a number of different genotypes was information that was not identified by most of the South-West Sydney network members.

Mai, Binh and Sarath talked about needles and syringes as possible ways to transmit hepatitis C, but did not identify the possible transmission risks from other injecting equipment, such as spoons, filters and water. Furthermore, Mai, Binh and Sarath also identified saliva as a possible hepatitis C transmission risk, which is not accepted as a risk for hepatitis C transmission in the literature (Alter, 2002, 2007). Mai knew that hepatitis C was transmitted through injecting equipment and could also be sexually transmitted: "You can contract hepatitis C through injecting needles and blood, or sexual". This belief was also expressed by Binh. However, Binh also identified saliva in his

understanding of hepatitis C transmission: “Yeah [hepatitis C can be transmitted] by sharing needles, that’s the first thing. Saliva, like anything with saliva, and sex... Blood, yeah, share needles and sex too”. Sarath explained that he was not exactly sure how hepatitis C was transmitted: “Oh, I dunno how hep C runs and that. Isn’t the hep C is saliva to saliva? No blood, no, no”. As saliva has been implicated in hepatitis A outbreaks (Mackiewicz, Dussaix, Le Petitcorps, & Roque-Afonso, 2004), it may be that Mai, Binh’s and Sarath’s knowledge about hepatitis C has been confused with transmission risks of other viral hepatitis types.

All South-West Sydney network members were aware there was treatment available for hepatitis C. However, knowledge about the medications used during the treatment regimes, treatment timeframes, side-effects and efficacy differed between the South-West Sydney network members. Hao had been made aware of hepatitis C treatment whilst in prison:

A lot of people in jail had [hepatitis C] and when they was through that treatment thing they were very sick and that puts a lot of people off. I know people with hep C and they don’t want to treat it because they have to work or whatever and they don’t want to do it because it takes too long. It takes 48 weeks or whatever (Hao, M28).

Hao’s account of hepatitis C treatment was formed in response to discussions that he had with other PWID in prison as to why they may not want to initiate hepatitis C treatment, including the negative aspects associated with undergoing a hepatitis C treatment regime. However, details of these negative treatment side-effects were only discussed by Hao in terms of general sickness and the impact of side effects on a person’s ability to maintain employment. Binh also thought about hepatitis C treatment in terms of a long timeframe. He explained:

It’s a risk [hepatitis C], yeah it is. Because hepatitis C once like you got it, it’s like takes a lot longer for a cure for that. I know there’s a cure for it but you have to be on a program like and it takes forever (Binh, M25).

Both Binh and Hao's identification of a treatment regime lasting either forever or 48 weeks in some ways does reflect what a hepatitis C treatment regime involves. However, hepatitis C treatment regimes are genotype dependent and can last between 24 and 48 weeks. It was not clear whether Binh and Hao were aware of this, as this was not expressed in their accounts of treatment. However, as both members identified the longest treatment regime it could imply that they tended to emphasise the apparently excessive length of hepatitis C treatment or they had come into contact with information regarding genotype 1 only, which has a longer treatment timeframe.

Mai was also aware that hepatitis C treatments were available, however, she did not believe that undertaking a hepatitis C treatment regime would result in a positive treatment outcome. As Mai explained: "Yeah of course [hepatitis C is a priority] because hepatitis C is very damaging ... at the moment that can't be cured". It is unclear where or how Mai had framed the impression that hepatitis C treatment could not clear the virus. Mai believed that she did not know anyone that was hepatitis C positive and did not report that she had known anyone who had undergone hepatitis C treatment. However, it may be that this understanding of hepatitis C treatment was not shaped by discussions with her partner, Hao, because Hao was much more knowledgeable about hepatitis C treatment, including its curative effects.

5.2.2 Beliefs about the seriousness of hepatitis C

All South-West Sydney network members were asked if they believed hepatitis C was serious. The various perceptions of these network members regarding seriousness have been organised into three thematic categories: comparing the seriousness of hepatitis C to HIV; hepatitis C as serious but situational; and no opinion on the seriousness of hepatitis C.

Dung, Hao and Tai believed that hepatitis C was serious, although less serious than HIV. As Dung explained:

I think [hepatitis C is] serious but I don't think it's deadly. I think HIV would be more, the most serious ... because I've seen the effects of hep C. A lot of my peers have hep C and I don't see any negative outcome of it: whereas, I hear a lot of negative outcomes from HIV (Dung, M32).

Dung's account prioritised the seriousness of HIV in comparison to hepatitis C which had been developed in response to the apparent lack of stories he had heard from other PWID about the negative health effects of hepatitis C. Given that hepatitis C is asymptomatic and side-effects may not be experienced for a number of years or decades, the lack of negative health effects described by Dung may have directly influenced his perceptions about the seriousness of hepatitis C.

Additionally, Dung also believed that HIV was more serious than hepatitis C because HIV was seen to cause death, while hepatitis C was not, and this was a perception that was commonly reported by South-West Sydney network members.

Like Dung, Hao believed that hepatitis C was serious but HIV (described by Hao as 'AIDS') was nonetheless prioritised over hepatitis C in terms of seriousness:

Yeah it's not an issue like AIDS or something. I dunno, like some people think hepatitis C is like a flu or something you know and they don't think it's that serious and other people know it's serious. It's serious, but not as serious as AIDS and that; you can still survive on hep C right? Yeah and you can get treatment for it, but AIDS you can't. [AIDS is more serious] because it is untreatable. Hep C is treatable but the scary thing with hep C is there are so many varieties or something, genotypes, whatever they call it and if you got it, you can get it again, and again (Hao, M28).

Again, hepatitis C was positioned as less serious and in the shadow of HIV in this account because hepatitis C was described as being 'flu'-like and therefore not that serious. Like Dung, Hao also believed that hepatitis C would not cause death. However, in contrast to Dung's explanation, Hao also believed that hepatitis C was both serious and frightening because of the number of genotypes

within the hepatitis C virus and the possibility that PWID could become infected and re-infected with a number of different hepatitis C genotypes. The belief about reinfection with different genotypes was not expressed by other South-West Sydney network members, including Hao's partner Mai.

Tai also interpreted the seriousness of hepatitis C with reference to HIV:

Yeah I reckon [hepatitis C is] serious but people don't really see it as really serious. Like, if you're a user you don't really see it as serious but non-users they see you and then yeah probably stay away from you. They think like not sharing drinks and stuff like that with you ... AIDS [is more serious]. I'm not really sure [why]? I don't really know what AIDS really is but yeah it's just I heard you die earlier from it and easier yeah and there's no cure for it as well (Tai, M27).

For Tai, the positioning of hepatitis C was different for those who injected drugs than those who did not. For those people who did not inject drugs. Tai believed that hepatitis C may be perceived as very serious and this belief could result in people taking overly excessive infection control measures around people they believed to be hepatitis C positive, such as not sharing drinks. Tai also believed that people who did not inject would also exclude people believed to be hepatitis C positive from social situations. With respect to PWID, Tai believed that they might not perceive hepatitis C to be as serious as those who did not inject drugs. What's more, Tai also positioned the seriousness of hepatitis C against AIDS without actually knowing what the HIV/AIDS virus entailed, except for the fact that he believed that AIDS would be more fatal and that there was no cure.

Mai expressed the most extreme response in terms of the perceived seriousness of hepatitis C. Mai explained: "No [I don't know anyone] with hepatitis C ... We all know the damage [hepatitis C] can do. So that's why we try not to hang around with anyone that's got it". This quote reveals that Mai's fear of hepatitis C transmission led to the practice of excluding people from her social network to avoid transmission. This exclusion occurred not only in the injecting environment; it also

encompassed wider social relationships. This practice was seen by Mai to offer a protection against hepatitis C transmission, a belief also articulated by her partner Hao. However, Hao reported that he only used exclusion in the injecting environment and so this did not encompass wider social relations from his perspective.

Hao also explained the seriousness of hepatitis C in terms of a perception of risk that was influenced by, and ultimately dependent on, the immediate situation he was in:

[Hepatitis C is serious] because it growing in numbers, people catching hep C you know. Yeah just from what I see in jail itself that's bad enough already imagine out here [in the community] too you know! [Interviewer: So, is Hepatitis C a priority?] Not at this time you know. Maybe while I was in jail, you were scared if you had a fight with someone like that or something but out here I'm pretty much alright (Hao, M28).

Hao's way of moderating this belief about seriousness since he had left prison was interesting because he believed he was more at risk of hepatitis C transmission from fighting and violence in prison, which he did not believe he would be exposed to in the community. Nowhere in this account does Hao identify the hepatitis C risk from injecting drugs and therefore his perception of the seriousness of hepatitis C may be underestimated when he is in the community.

Sarath was the only South-West Sydney network member who had not made a conscious judgement regarding the seriousness of hepatitis C. As he explained: "I wouldn't have a clue [if hepatitis C is serious], I dunno. No [I don't think about it often]. Only when I'm injecting, it just come to my head, 'oh hep C, hep C'". Given Sarath's poor knowledge of hepatitis C (see previous section), it is not surprising that he had not thought about hepatitis C often or that he had not made a judgement in relation to its seriousness. Although a judgement in relation to seriousness was not described by Sarath, hepatitis C was not completely ignored. Sarath explained that the impetus for thinking about

hepatitis C, and its seriousness, would most likely occur at the point of injecting (as identified in the quote above).

5.3 Hepatitis C-related communication

The following section will explore reported instances of hepatitis-C related conversations between network members, including general discussions and disclosure of hepatitis C antibody status.

Within this network, as was observed in the previous chapter also, very little hepatitis C-related communication appeared to occur and this absence was seen to be the direct result of the perceived, or real, consequences of initiating or contributing to such conversations. Therefore, the following section will focus on the analysis of South-West Sydney network-based communication with respect to the theme of absence and consider what factors may have contributed to that.

Additionally, due to an absence of hepatitis C antibody disclosure within the South-West Sydney network, this analysis will also report on a practice of inferring hepatitis C antibody status on other network members, as we also saw in the previous chapter.

5.3.1 Absence of discussions about hepatitis C

The absence of hepatitis C-related discussions within the South-West Sydney network was so pervasive that no network member could recall a recent time where a discussion about hepatitis C transmission, prevention or treatment had occurred, but the reasons behind this silence were viewed differently by different network members.

Dung reported that he had extensive knowledge of hepatitis C, virus genotypes, transmission risks and treatment options; however, he also explained that he had not had a conversation about hepatitis C with any of the South-West Sydney network members:

I guess because I'd probably think they already know [about hepatitis C]. I guess the only time I would say something is if I see it. If I see the unsafe practices then I'd let

them know that like the better way for it ... I think a lot of time [information] it would have to be given to them. There's only like yeah, only a small number of people that would actually go and seek that information (Dung, M32).

The absence of hepatitis C-related conversations between Dung and other South-West Sydney network members was explained as the result of a number of factors. At the most pragmatic level, Dung did not inject or socialise with other South-West Sydney network members and therefore he would not be present in the injecting environment, which Dung saw as the most appropriate place to initiate these types of discussions. Dung also believed that most people would already have knowledge about hepatitis C transmission, making these discussions redundant. Interestingly, and contrary to his initial response about PWID knowing about hepatitis C, Dung also suggested that hepatitis C-related information was not a topic that other PWID may seek information about. As Dung did not recall having hepatitis C-related discussions with other people in the South-West Sydney network, I asked him:

Say you learned something new about hepatitis C, what sort of incentive would there be to share that sort of information?

If there was information on hepatitis C, I think it might be more incentive just for the well-being of another individual I guess so, plus that information is free like you know (Dung, M32).

For Dung, the perception that hepatitis C-related discussions were not taboo or restricted also influenced Dung's beliefs about the ease with which hepatitis C-related discussions could be initiated. Furthermore, Dung also suggested that a motivation for initiating or discussing hepatitis C within social networks of PWID would be to encourage health and well-being: discussions which Dung believed did not involve any perceived social costs. However, Dung's view was markedly contrary to all other South-West Sydney network members who identified a range of potential social costs to initiating and discussing hepatitis C with other network members.

Mai explained that she did not discuss, or initiate, hepatitis C-related conversations, even with her partner Hao. In fact, the question about discussing hepatitis C was so unusual that Mai responded to this question with surprise: “well what would you talk about that [hepatitis C] for? ... Because you know, like when you haven’t got it you know, so yeah we don’t talk about it”. For Mai, hepatitis C was not a topic of general discussion because she did not believe that she was at risk of contracting hepatitis C (see disclosure of antibody status discussed below). Although Mai believed that there was no reason to engage in hepatitis C-related discussions, this absence of discussions between her boyfriend, Hao, and herself, resulted in differences in knowledge about hepatitis C transmission and treatment between the two. For example, Hao was knowledgeable about the transmission risks associated with other injecting equipment as well as details about hepatitis C treatment efficacy, of which Mai was not aware. Further, Mai believed that saliva was a transmission risk and Hao was aware that saliva is not a hepatitis C risk. Mai also believed that sex was a hepatitis C transmission risk; however, Mai did not speak of sexual transmission in depth and this belief may also be framed in terms of bodily fluids and sexual transmission (such as for hepatitis B).

Hao also explained that hepatitis C-related conversations were not usually initiated or discussed between himself and Mai, or other South-West Sydney network members. However, unlike Mai, who did not participate in hepatitis C-related discussions because she did not believe that she needed to engage in these, Hao’s explanation of a lack of discussion regarding hepatitis C appears to be influenced more by fear. Hao explained that discussing hepatitis C increased the risk that his drug use might be disclosed to family and community members he did not want to have access to that information. As a result, Hao identified that if he was to talk about hepatitis C, he would find it “easier to talk to a stranger, me personally, than to someone I know because you don’t know them and you not scared they gonna tell someone else that knows you or something you know”. Although all members of the South-West Sydney network identified cultural influences on their injecting

practice (see social network dynamics), Hao was the only network member to make connections between family, community and reluctance to initiate hepatitis C-related communication.

Interestingly, Binh was the only South-West Sydney network member who reported having hepatitis C discussions with other network members. Binh explained “that just like sometime, like you know, we sit down, we talk you know what I mean [about] everything and Hepatitis C is like come up and we talk like about Hepatitis C”. However, he could not recall an instance where a hepatitis C-related conversation about transmission, prevention or treatment had occurred between himself and other South-West Sydney network members.

5.3.3 Absence of discussions about hepatitis C status

Within the South-West Sydney network membership, the absence of discussion or disclosure of hepatitis C antibody status was even more pervasive than the silence surrounding hepatitis C more generally. This section will therefore explore discussions about disclosure and the factors that appeared to silence these types of discussions within the South-West Sydney network. Although Mai explained, “I don’t know like sometime a question may come up like ‘have you got it’?”, with the exception of hepatitis C antibody disclosure between herself and her partner Hao, Mai did not recall other conversations involving disclosure within the South-West Sydney network. This was similar to Sarath, who had previously reported that he had had discussions with others outside of the South-West Sydney network about his positive status; however, these discussions were not reported to have occurred with other members of the South-West Sydney network. Sarath explained “I don’t know if they have hepatitis C. I wouldn’t know, I never ask”.

Tai also explained that he would not initiate conversations that may result in the disclosure of hepatitis C status among other South-West Sydney network members:

Never really asked them [if they have hepatitis C]. I dunno [why]. It's more their private information, even though we have a right to know sort of if we using together and that... Yeah but then pissed off because what if you're the other person and you wanted to know about that information and that. So it makes it hard (Tai, M27).

Tai's response about why hepatitis C disclosure did not occur between members of the South-West Sydney network highlighted an implied tension between disclosing and not disclosing hepatitis C status. This tension was framed around a persons' hepatitis C status being perceived as 'private information'. However, when PWID were injecting together this desire for privacy is overridden by the right to know if there is a risk of acquiring hepatitis C risk.

Tai also explained why he had not initiated discussions with other South-West Sydney network members about his own positive hepatitis C test result:

Yeah, sort of like uncomfortable to talk about [hepatitis C]. Yeah and 'cause if you have it you don't really want to tell anyone and stuff. Just the fact that they might look at you differently and yeah 'cause a lot of people, how do you call it, like stereotype sort of thing. A lot of people don't understand it and they think like if you have it yeah they can't go near you, or touch you, or share things with you and that. [It] makes me feel like awkward sort of, and sort of sad like because it's not like normal or anything ... [Hepatitis C is] also an awkward topic to talk about sort of. Just that 'cause you just, you're scared, you don't know what people are gonna think of you. Yeah that's the main thing, like they might judge you and look at you differently (Tai, M27).

Tai described how a lack of knowledge and understanding of hepatitis C could result in people who were hepatitis C positive being subjected to stigmatising and excessive infection controls among their peers, such as refusing to touch or share things with the person living with hepatitis C, or

excluding them from social networks: practices that were identified by Mai and Hao as well. Tai also identified a range of emotions that arose when thinking about discussing his hepatitis C status and which influenced his decision to avoid discussing hepatitis C with other people. The negative responses identified by Tai in relation to the disclosure of a positive hepatitis C status highlight how a fear of hepatitis C-related stigma directly affected communication processes among this network of PWID.

Conversely, Binh believed that hepatitis C-related discussions about antibody status had occurred between himself, Tai and Sarath because he claimed that they talked about everything:

I know for a fact that none of them have hepatitis C. Yeah [they would tell me]. Yeah, always 'cause we kind of like family, brothers, you know what I mean ... We ask each other if you like you got hep C or that you know and it's like a friend, 'you know me, just ask' you know what I mean? [This happens] just like sometime, like you know we sit down, we talk you know what I mean about everything and hepatitis C is like come up and we talk like about hepatitis C (Binh, M25).

Binh also suggested that they had had conversations with other South-West Sydney network members about hepatitis C, including discussions about disclosure. However, these accounts were not confirmed by the network members with whom Binh reportedly discussed hepatitis C status. For example, Binh recalled having hepatitis C-related conversations with Sarath and Tai; however, Sarath and Tai were strongly adamant that they had not discussed their hepatitis C status with other South-West Sydney members. As is implied in the quote above, Binh may have believed that because he had a close-knit relationship with Tai and Sarath, they would have communicated their hepatitis C positive status to him. As it appeared that disclosure had *not* occurred between the three, Binh assumed that both Sarath and Tai were hepatitis C negative and the rest of Binh's account about hepatitis C discussions between the three was woven around this assumption.

Although disclosure of hepatitis C antibody status was not common within the South-West Sydney membership, these discussions were reported to occur between those South-West Sydney network members who were in a sexual relationship and between Sarath and Hao and other PWID who were not members of the South-West Sydney network. Mai explained her lack of engagement with discussions about hepatitis C antibody status was bound by her belief that she had been tested (albeit two years prior) and therefore did not need to engage in these discussions because she had done so once with her boyfriend and both were hepatitis C negative at the time they were tested. Again, the resulting lack of engagement was explained as the direct result of her belief that there was no risk of hepatitis C transmission between Mai and her boyfriend. Hao's account confirmed that he and Mai had disclosed their hepatitis C status to each other at the start of their relationship: "Oh when we first got out of jail we asked could we get tested and that. No we talk about [hepatitis C] and that's it, it's finished. We don't bring it up every day". However, this discussion was the only hepatitis C-related conversation reported to have occurred between the two.

Sarath also recalled a time where he had disclosed his positive hepatitis C status to people outside of the South-West Sydney network when he had been injecting with an Anglo-Australian PWID network:

I reckon if there was no fits around, like say there's only one fit there, you talk about [hepatitis C]. Yeah but not all the time you know. Sometime I run out yeah and then they [the Anglo-Australian network members] have to use my old one and I tell them I got hep C and they go oh "it doesn't worry me"... [They don't care] 'cause they don't know what it feels like. Maybe they don't know what hep C is you know. If they get it and they feel sick and stuff then they will realise, but because hep C is a thing that hits you in the long run, not straight away, that's why people don't care I reckon (Sarath, M28).

Sarath suggested that the point of injection could be a catalyst for initiating discussions about hepatitis C, especially when other PWID ask if they can borrow or use injecting equipment. However, in the above example these discussions were believed to be solely focused on the disclosure of hepatitis C status rather than any specific or detailed discussion about the routes of hepatitis C transmission or related information. Sarath believed that other PWID would choose to reuse equipment even after being told that the person who used the equipment first had hepatitis C because they may not know about the effects of hepatitis C and may not, therefore, understand the long term consequences of hepatitis C transmission. However, the reasoning behind the actual reuse of equipment in this example cannot be known as the person borrowing the equipment did not participate in the study.

Hao also recalled an instance where he had discussed, or asked another unknown PWID, about hepatitis C antibody status, whilst they were incarcerated:

I asked them how they got it, I dunno, 'cause I remember I ask [an unknown person] when he was in jail with me, and he was here you know, and he told me he had hep C, and he goes, he told me a silly story that every person will have it because something about the war time and I go no that's not true. So he was one of them person and just talk about it in that (Hao, M28).

The above example described by Hao is interesting because it highlights how he had initiated discussions about hepatitis C, which was a practice that Hao previously described as avoiding in everyday life outside of prison. Although it is not clear why this person had disclosed to Hao, this person was not identified and did not participate in this study. However, this example highlights how different settings influence hepatitis C discussions and disclosure.

Although Dung did not recall an instance where he had discussions about hepatitis C antibody status with other PWID, he suggested that hepatitis C was ubiquitous and not stigmatised and therefore

conversations involving disclosure would occur if necessary. He explained: “I guess because hep C is not really all that taboo. Like I said, a lot of people have it. No one is ashamed of admitting to it”.

Despite Dung’s assertions, during the research process he did not identify any instances where other PWID had disclosed a positive hepatitis C infection to him. Furthermore, Dung’s perception that conversations involving disclosure would occur and involved no social costs was not voiced by other South-West Sydney network members.

Even though explicit disclosure was uncommon, it was more common to infer a hepatitis C antibody status on other network members. Within these inferences, a positive hepatitis C antibody status was inferred on all South-West Sydney network members by Dung, which may have been influenced by his perception that hepatitis C was ubiquitous amongst PWID populations. A positive hepatitis C antibody status was also inferred on other network members by Mai and although the reasons behind this inference were not clear, as Mai’s perception could have been influenced by her belief about the perceived ubiquity of hepatitis C among populations of PWID as well as the belief that hepatitis C was transmitted by saliva, which would increase the ease at which hepatitis C could be transmitted. Additionally, Hao inferred a positive hepatitis C status on other South-West Sydney network members, however, he did not identify where or why this inference was made. Binh was the only member that inferred a negative status on someone who self-reported as hepatitis C positive. In this example, Binh believed that Tai was not hepatitis C positive because they were close friends, like brothers, and Binh believed that due to this relationship Tai would have disclosed. An exception to inferring a hepatitis C antibody status was described by Sarath and Tai who reported not having these types of discussions and therefore not knowing the hepatitis C antibody status of other South-West Sydney network members.

5.4 Social network dynamics in the injecting environment

The following section will explore the social network dynamics that shaped injecting practices within this network. This will include an analysis of the practices, rules and roles that operated in injecting settings, such as injecting hierarchies, not injecting in public, not injecting with others, cleaning used equipment and issues of image management. This section will also speculate on why these social network dynamics occurred and how they may have positively or negatively impacted hepatitis C risk transmission risk.

5.4.1 Injecting roles and hierarchies

As identified in the previous chapter, an injecting hierarchy is created when one individual injects before another in an injecting episode and this sequencing has the potential to directly influence hepatitis C transmission if injecting equipment is shared. Although none of the South-West Sydney network members described the injecting episode as a possible hepatitis C transmission risk, the accounts provided by these network members indicate that injecting hierarchies were present and formed a central part of injecting practice for most South-West Sydney network members. These hierarchies can therefore be interpreted as influencing hepatitis C transmission risk for individual members. For example, during any injecting episode with other South-West Sydney network members, Sarath explained that he always injected first because he was the one who would “test [the heroin] out”. Going first in any injecting episode may therefore reduce Sarath’s contact with used equipment but it would also mean he took on other risks in the form of testing the drugs’ strength and purity, such as overdose.

Tai explained that he believed there was no apparent hierarchy in the injecting order with Binh and Sarath:

Yeah, we split it all equally and then we chip in to get the drugs ... Probably all of us would but yeah we'd all be there ... I don't know [who would inject first]? I think, I dunno, it's just sort of at the same time really because once it's done we just all put our fits in and then just draw it up at the same time (Tai, M27).

Tai's response to questions about the practice of injecting was based around notions of equality, including the process of purchasing, preparing and using drugs through an equal split. In Tai's case, the inability to recall detailed information about the injecting environment and injecting practice may be the result of injecting practice that is based on an habitual behaviour, which occurs when people may not be consciously aware of the processes and practices used in the preparation and injecting event. Without a conscious awareness of this, recall and actual description of the processes and practices used in the injecting environment can be impossible. Alternatively, the lack of detail identified in Tai's description of the injecting environment could also be because he had not injected for five months and therefore he could not recall the detail of the injecting episode.

Hao explained that there was an injecting hierarchy when he and his girlfriend, Mai, injected together:

Yeah, [Mai] she does [inject first]. I dunno [why]? It's just how it's always been. Pretty much, yeah, every single time. No [we don't have rules] it's just that we know what to do. She does [the mixing and goes first]. Yeah, she always have the money. Not really 'cause she's a girl, you know, may be wrong to say that ladies first I don't know (Hao, M28).

So in this injecting hierarchy, Hao was not in charge nor prepared the drugs and he also injected second in any injecting episode. Although Hao did not describe this practice as a rule, he believed that it the result of Mai being more financially able to purchase the drugs. In describing this practice, Hao also suggested that there could be a gender role that resulted in Mai preparing drugs and injecting first.

Mai also described an injecting hierarchy when she and Hao injected together, however, she interpreted this hierarchy differently:

Me [I mix up], I just do it because I dunno. Yeah he [Hao] can't do it properly, he can't measure it properly and stuff ... He's more dopey you know. He can't do it properly. Like because it costs so much, if he spills it you know, or if he like wastes a bit or drops it, it's just a waste and it's not easy to get money (Mai, F24).

From Mai's perspective, she assumed the drug preparation role because she had greater knowledge, skills and experience in preparing drugs. As well as taking charge of preparing the drugs, Mai also controlled the couple's access to both drugs and sterile injecting equipment because she had the finances required to purchase their drugs and owned the car to access the dealer. Supporting this account were explanations of the rules initiated by Mai about not injecting with others and never injecting in public, which are discussed below. These rules almost always located control in an injecting episode with Mai.

5.4.2 Only inject with each other and not in public

Mai and Hao also described a rule of not injecting with other PWID and not injecting in public places. Hao explained that "we don't use with anyone else. Never. Ever. Since I [have] been with her we never use with anyone else" (Hao, M28). This rule was initiated at the beginning of Mai and Hao's relationship by Mai and maintained by both Mai and Hao in a conscious effort to minimise their contact with PWID who were believed to be hepatitis C positive. As well as only injecting with each other, Mai and Hao were the only South-West Sydney network members who did not inject in public places:

Always [inject at home] because if you get caught in the car park or something then you get busted by police and it not worth it ... I got a very strict rule about that, that I don't do it anywhere but at home ... Yeah, Hao he not allowed to do it either. If he wasn't with me then I wouldn't know (Mai, F24).

Mai's rule about not injecting in public places ultimately reduced her risk of hepatitis C transmission and was also a protective factor for both herself and Hao. However, given that Mai lived with her parents, which required her to hide her drug use, and Hao was in the process of moving into his own home, it is unclear as to whose home Mai was referring to in this case. Mai also explained that the ability to enforce these rules was limited because when Hao was not with her she couldn't be sure what he was doing. Although Hao was adamant early in his interview about only injecting with Mai, in later responses Hao explained that "if I do use with them (other South-West Sydney members) like on my own or whatever but I rarely use with them anyway". If Hao was injecting with other South-West Sydney network members, Mai's assessment that she was not at risk of hepatitis C transmission may not be correct.

Interestingly, although Hao reported that although he would not inject with anyone else in the South-West Sydney network because 'he feared getting hepatitis C' he also explained that if Mai had hypothetically contracted hepatitis C, this would not have changed his relationship or injecting practice. Hao explained:

Yeah [I would hypothetically have injected with Mai even if she was hepatitis C positive] ... Just to go through what she go through maybe ... No, they [the other South-West Sydney network members] not worth it you know. Maybe with [Mai], I can get treatment with her or whatever you know go through what she go through ... Because I personally trust her you know (Hao, M28).

The influence of love and trust within Hao and Mai's relationship could be seen to somewhat override Hao's determination to avoid contact with hepatitis C. If Mai had been hepatitis C positive, Hao explained that if he contracted hepatitis C from Mai, they would share this experience together. This suggests that the trust and love in this relationship overrode the fears of transmission that could occur with other networks members, who were described by Hao as 'not worth it'.

5.4.3 Cleaning used injecting equipment

All South-West Sydney network members spoke of the difficulty in accessing sterile injecting equipment when required because of a lack of services in the South-West Sydney area and the fear of being seen by family and community when purchasing equipment in the South-West Sydney area. As it was common to not have enough sterile injecting equipment to meet their injecting needs, Mai spoke of cleaning used injecting equipment when required:

Oh you wash them [used needles and syringes] out with hot water. A lot of hot water and just you keep just rinsing it out and you can tell [when it's clean] because there's like no blood in it or anything. [It's] very disgusting. I mean it's normally like always cleaned out anyway and in this situation you just change them or else if you had to just keep washing out with hot water. It gets all the blood out like you can't see it (Mai, F24).

Mai's process of cleaning a used syringe was necessary because of the structural, institutional and financial barriers that she and Hao experienced in trying to access sterile injecting equipment when required. Although Mai had initiated a practice to clean used syringes, the process described by Mai was ineffective in reducing hepatitis C transmission in a number of ways. Using hot water is not a process recommended to clean injecting equipment because this practice does not eliminate or remove blood contained in the syringe and therefore does not reduce the risk of hepatitis C transmission (Nathani, Iversen, Shying, Byrne, & Maher, 2010). Additionally, the use of hot water to clean injecting equipment has been shown to congeal blood, which results in blood sticking within the barrel of the syringe (Australian Illicit Injecting Drug Users League, 2009). Mai also described how she relied on being able to visually identify when her syringe had been adequately cleaned; however, this process was also flawed as small particles of blood may not always be visible. As it was Mai's role to clean the used injecting equipment, Hao did not speak of the practice or how he would clean used equipment himself. Furthermore, it was not clear whether Hao was aware that the

practice used by Mai to clean used injecting equipment was not effective in reducing the transmission risk of hepatitis C.

Due to restrictions on sterile equipment access, Tai also described a need to clean used injecting equipment. Tai explained that he had previously used “hot water [to clean used equipment] but I just found out that that’s bad ‘cause the hotter the temperature the bacteria grows in it or something like that” (Tai, M27). Although Tai explained that he had changed his process in relation to this new knowledge about bacteria, he was still of the belief that his cleaning technique provided a protective mechanism against the transfer of hepatitis C. Furthermore, due to a lack of interaction and discussion with other South-West Sydney network members, Tai’s new knowledge that led to a change in his cleaning practice had not been communicated to other South-West Sydney network members. Although the dynamics related to cleaning injecting equipment reported this network may appear to be influenced by understandings and beliefs, the network dynamics surrounding the lack of hepatitis C-related communication within this network could also be seen to have a direct effect on how these practices remained unchanged: even when one network member became informed and subsequently changed their practice regarding cleaning equipment, the knowledge and change did not occur at the network level.

5.4.4 Hiding drug use from family and community

All members of the South-West Sydney network discussed the need to hide their drug use from family and other community members in the South-West Sydney area. This involved a number of practices including concealing themselves when purchasing drugs and injecting equipment and managing their social image by hiding injecting track marks and scars. Although the need to hide drug use from family is something that most PWID have to do at some, or all, stages of their injecting careers, members of the South-West Sydney network placed particular weight on the importance of these practices for maintaining connections in a migrant community context. For example, Binh

described how the stigma of being labelled as someone who injected drugs in the Vietnamese community had serious consequences not just for the individual but for the whole family:

Because like Vietnamese culture, I mean they look down on [you], in a way I feel bad. They look down on me but kind of like look down, not look down on my parents but what's the word? Embarrassed. Yeah they do, they feel embarrassed because [it] make my parents get bad name you know what I mean. They say 'your son on drugs' and things like that. Of course my parents get embarrassed (Binh, M25).

Due to these strong cultural connections, disclosing drug use to friends and family members had serious potential to discredit the person who injected drugs, which created embarrassment and shame for the family unit as a whole. Although this embarrassment and shame may also be an important issue for non-Vietnamese migrant PWID, South-West Sydney network members particularly stressed how important it was to hide their drug use because the consequences were likely to be a dramatic loss of connection and family reputation within the Vietnamese community.

The consequences of Tai's injecting drug use also included exclusion from his extended family:

Really dislike it [my injecting drug use]. Like my cousins don't even talk to us anymore and my aunty like doesn't want me coming over. [She] like banned me from coming over. Not banned me really but yeah she told my mum not to let [me] come over and that 'cause like scared we rob them or stuff like that yeah (Tai, M27).

For Tai, there was a need to hide his drug use from both his immediate family and the wider Vietnamese community. In the example above, Tai's injecting drug use had become common knowledge within the immediate family unit and this had resulted in him being prohibited from meeting his family members. Alongside his drug use, Tai had also been labelled a thief and this combination of factors resulted in rejection from his family.

As a direct result of needing to hide drug use from family and community, all South-West Sydney network members spoke of the need to travel to other suburbs to purchase sterile injecting equipment because of the fear of being seen. Mai and Hao travelled at least 30 minutes by car to purchase equipment and Tai described travelling to suburbs other than the one he lived to purchase injecting equipment. Hao explained that they travel to another suburb to purchase injecting equipment: “because you don’t want you know someone telling your parents that they saw me getting a pack of fits you know”. The fear of South-West Sydney network members being seen purchasing injecting equipment had real and substantial consequences. Sarath explained that if he was seen by his mother, sister or other person who knew him, there was a real risk that he “would probably get kicked out of the house”. As all South-West Sydney network members, with the exception of Hao, lived with their parents, the risk of being seen purchasing injecting equipment could impact on their home life and therefore be a threat to stable family-based accommodation. This risk also influenced the South-West Sydney network members’ ability to hold sufficiently large numbers of sterile injecting equipment in their home for fear of the equipment being found by another a family member.

5.4.5 Image management and blending in

Mai, Binh, Sarath and Hao described a strategy of maintaining a normal appearance, image management, to hide drug use from family and community and they believed that these practices helped them to blend in and to avoid being identified as a PWID. Mai explained how image management was able to somewhat hide her injecting drug use from family:

Family they have like rough idea [that I inject drugs] but like they haven’t seen me do it or nothing like that you know. Like they know I’m on drugs, I been on it for a while and if I don’t take care of myself then of course they know but otherwise they don’t know (Mai, F24).

Although Mai's family were aware of the history of her injecting drug use, by 'taking care' of herself and maintaining what she perceived to be a 'normal appearance', Mai explained that she was able to somewhat reduce her family's awareness of her current injecting drug use. Hao also spoke about the need to hide his injecting track marks to blend in:

[Injecting drugs] is very wrong, bad, yeah, especially with the parents and that you know you don't want to let them know that you inject, you hide your track marks whatever. It just they look down on you straight away. That's it, you don't want them to know. Some parents I know actually disowned my mate, just got kicked out recently. Because we very strict culture like as in you know our parents. We got strict upbringing and you know you get busted for something like that [injecting drugs] some parents would disown you and I don't know if ever they take you back (Hao, M28).

Culture and strict upbringing are clearly important concepts for Hao in motivating him to hide his injecting drug use, particularly any visible track marks. Like Sarath, Hao also described the consequences of being asked to leave the family home and being disowned when family became aware of injecting drug use. Blending in also involved the practice of changing injecting sites. For example, Sarath had learnt to inject into his neck whilst in prison to so as to hide his injecting marks from prison offices. Sarath continued this practice when released from prison because he believed that it assisted in hiding his injecting marks from his family and community members.

Issues of blending in may serve to reduce the social risks of being identified as a person who injects drugs; however, when coupled with other factors experienced by the South-West Sydney network members, the impact of image management on reducing possible hepatitis C transmission may be limited. For example, Mai and Hao both spoke of the need to hide injecting track marks from their family. However, due to the inability to access sterile injecting when required, they routinely reused their own injecting equipment, which would increase injecting track marks and scars. For Sarath,

moving his injecting site to his neck may have been useful to hide his track marks whilst in prison; however, once he had been released from prison he had to start injecting in public places and this may also have mitigated the effects of image management on hepatitis C risk since he would need to rush the injecting process.

5.4.6 Exclusion from the injecting environment as a response to hepatitis C

Dung described absenting himself from particular injecting environments, as a protective mechanism that he used to reduce his contact with hepatitis C:

I'd just educate them if I could. Yeah I guess I would ... I just wouldn't use with them
yeah if they didn't take the information on board and continued their unsafe
practices. I wouldn't use with them (Dung, M32).

For Dung, avoiding particular injecting networks could be viewed from two perspectives. In the first, Dung identified that at the time of interview claimed he did not inject with others. In this account, Dung could be seen to avoid injecting with other PWID to minimise his risk of hepatitis C. In the second, Dung also explained how he would use the sanction of exclusion of others when he believed other PWID were injecting unsafely and continued to inject unsafely, after being told to change their practice. Although Dung did not identify an example of putting this protective mechanism into practice, the fact that he typically injected at home and generally alone could suggest that Dung's both avoided others and absented himself from injecting environments as a response to hepatitis C risk.

5.4.7 Exclusion from social networks as a response to hepatitis C

Mai also described the use of exclusion as a protective factor to minimise her contact with hepatitis C. However, Mai's practice went further than Dung's and not only included the injecting environment; she also enacted forms of exclusion in her broader social world:

I do not hang around with anyone like that [who has hepatitis C] or else. Sometimes you just do the stupidest things, I don't know, without thinking properly. You know [I would know if they had hepatitis C] because you just know. Either like somebody else knows, or they've told somebody like if they're honest and upfront they'll tell you (Mai, F24).

Mai explained that she does not socialise or inject with anyone that she believes to be hepatitis C positive and although Mai had not had a conversation with members of the South-West Sydney network about their hepatitis C status, she explained that knowing another persons' hepatitis C status was either implied or the result of other people knowing and discussing this. Mai explained that excluding PWID believed to be hepatitis C positive from both her social and injecting worlds was a strategy employed to manage and minimise the risk of transmission of hepatitis C for both her and her partner Hao. However, the practice of excluding PWID from social networks based on perceived positive hepatitis C status was ultimately based on inferred knowledge that used negative judgements and social sanctions attached to being hepatitis C positive.

Hao also spoke about avoiding others as a protective mechanism for himself in relation to hepatitis C:

Yeah [Sarath and Tai are hepatitis C positive]. [I don't inject with them] because they got hep C. How do I look at them? Like they just got bad luck like they didn't know about it. I don't hate 'em or anything like they still my friends. [I don't inject with them] because I scared of getting, catching Hepatitis C. If I do use with them like on my own or whatever but I rarely use with them anyway (Hao M28).

Like Mai, Hao was making an assumption here about who he believed to be hepatitis C positive. Although Hao explained that he would not inject drugs with Sarath and Tai because he believed they were hepatitis C positive, Hao's exclusion practices were not as severe as Mai as they only focused on the injecting environment. Furthermore, this practice was not based on negative labelling related

to hepatitis C, as was the case with Mai. Rather Hao explained that he believed that Sarath and Tai had contracted hepatitis C through 'bad luck' and so their hepatitis C status did not change their friendship dynamic.

5.5 Summary of the South-West Sydney network

Knowledge regarding hepatitis C among the South-West Sydney network was somewhat limited. All network members had smoked heroin for at least five years, before transitioning to injecting and this timeframe should have created a large window of opportunity for members of the South-West Sydney network to access information about hepatitis C. However, this opportunity had not been realised. Although all South-West Sydney network members were aware that used needles and syringes were associated with an increased risk of hepatitis C transmission, at least half of the network members were unaware of the transmission risk from other injecting equipment. Further, these same network members were of the belief that saliva was a possible hepatitis C transmission risk. Although all South-West Sydney network members perceived hepatitis C to be serious in some way, this was not based on a complete or detailed understanding of hepatitis C transmission risk or treatment efficacy. Further, at least half of the network understood the seriousness of hepatitis C in relation to HIV. When this comparison was made, hepatitis C was viewed as less serious than HIV due to a lack of negative health consequences observed in peers, the belief that there was no treatment for HIV and that HIV was deadly, whereas hepatitis C was not.

There was a complete absence of hepatitis C-related discussions reported to have occurred between the members of the South-West Sydney network because of the belief that there was no need to engage in these conversations or because of fears of the social consequences of initiating these discussions. This lack of discussion exacerbated the differences in hepatitis C-related knowledge between South-West Sydney network members, even those in long-term sexual relationships. This

lack of discussion also meant hepatitis C-related knowledge that individual members held was not shared or confirmed among the South-West Sydney network to enable corrections where necessary.

Due to the perceived consequences of discussing hepatitis C within the network, South-West Sydney members who were hepatitis C positive did not disclose this to other members and as a result, a practice of relying on inferred or implied hepatitis C status of other South-West Sydney network members was common. Reliance on inferred hepatitis C status of others influenced risk assumptions. Furthermore, the practice of excluding those believed to be hepatitis C positive from injecting and social networks was common in the South-West Sydney network. Although this practice could potentially be effective in reducing hepatitis C transmission, socially excluding people believed to be hepatitis C positive could be seen to worsen the perceived stigma attached to hepatitis C. Additionally, the inability to disclose a positive hepatitis C antibody status also negatively influenced the level of support that those who were hepatitis C positive could receive from other South-West Sydney network members.

With the exception of Binh and Sarath, all South-West Sydney network members spoke of initiating practices and rules that they believed would minimise their contact with hepatitis C. However, the effectiveness of practices were somewhat compromised because members were not aware of the most effective way to clean equipment and did not discuss this practice between themselves. Other practices, such as image management were also utilised by all South-West Sydney network members. However, the fear of drug use becoming known by family and community led to other practices, such as public injecting and not stockpiling of sterile injecting equipment at home, which may have reduced any impact that image management practices could have had on hepatitis C transmission risk. Injecting hierarchies were also evident within the South-West Sydney network and although these hierarchies may reduce (or increase) an individual's exposure to hepatitis C, they were not consciously undertaken nor were they perceived to operate as practices that reduced risk;

rather, these hierarchies were influenced by broader social dynamics relating to the economics of drug and equipment access, and potentially some issues relating to gender within intimate partnerships.

The next chapter will report on the research conducted with the network of PWID based in the quite different geographic and cultural environment of South-East Sydney. The structure of that chapter will reflect that which was followed in this and the preceding chapter, including hepatitis C-related knowledge and beliefs, hepatitis C-related communication and the social network dynamics that were evident in the injecting environment of South-East Sydney network members.

Chapter 6 South-East Sydney network

6.1 Study site overview

6.1.1 The setting

The South-East Sydney study site was a large inner-city area in the City of Sydney, comprised of parts of the central business district and a number of inner-city residential suburbs. Most of Sydney's entertainment venues fall within the study site boundaries, including the red-light district of Kings Cross and the areas of Surry Hills, Darlinghurst and Potts Point, where some hotels, restaurants, bars and clubs operate on a 24 hour basis. The study site was also home to most of the NSW government and law enforcement offices, such as the NSW Parliament, the largest Local Area Police Centre in NSW, the Australian Federal Police (AFP) and the Local, Family, Supreme and High Courts.

In 2011, the South-East Sydney area had a population of 183,494, of which 62.1% were Australian citizens (Australian Bureau of Statistics, 2011d). Of these people, 44% were Australian born, 1.3% identified as Aboriginal and Torres Strait Islander and 42.4% were born overseas. The largest group of people migrating to the South-East Sydney area were from the United Kingdom, China and New Zealand. 29.9% speak a language other than English; with the three largest non-English speaking languages including Mandarin, Cantonese and Thai (Australian Bureau of Statistics, 2011d). The South-East Sydney area was also home to one of the largest populations of homeless people in NSW and Australia. In 2011, the primary and secondary homeless population in South-East Sydney was 755 people, including 307 rough sleepers and 448 occupied hostel beds (City of Sydney Council, 2011) and 500 people were listed in crisis accommodation, including 50 families (Wesley Mission, 2011).

The South-East Sydney study site was one of the best serviced areas for PWID in NSW. Australia's first legal needle and syringe program began operation in 1986 in South-East Sydney (Australian National Council on Drugs, 2006) and was also home to the only Medically Supervised Injecting Centre (MSIC) in the southern hemisphere (Van Beek, 2003). At the time of interview, a diverse range of health and injecting related services were available to PWID via a range of service models and organisations, including primary and secondary NSP services delivered by the NSW Health Department and Local Health Districts. Prominent non-government organisations, such as the NSW Users & AIDS Association (NUAA), Hepatitis NSW and the AIDS Council of NSW (ACON) also provided access to sterile injecting equipment and health information. In addition, numerous pharmacies in South-East Sydney provided access to injecting related equipment for PWID. Those pharmacies participating in the NSW Pharmacy Fitpack Scheme were permitted to sell new needles and syringes or exchange used equipment at no cost, whilst some other pharmacies distributed injecting equipment independently of the NSW Fitpack Scheme (NSW Department of Health, 2013b).

Given the close proximity of the study site to a number of national research centres specialising in illicit drug use and hepatitis C research, significant numbers of research projects involving PWID have been conducted in the area. These studies have found, for example, that South-East Sydney has well established services for hepatitis C and extensive needle and syringe programs (Bryant & Hopwood, 2009). PWID in Sydney have been shown to also have a reasonable knowledge of hepatitis C transmission and infection (Doab, Treloar, & Dore, 2005), however large gaps in knowledge have also been observed in relation to knowledge of hepatitis C treatment and treatment outcomes (Doab et al., 2005; Treloar, Hull, Dore, & Grebely, 2012). It must also be acknowledged that although PWID in South-East Sydney have been extensively documented in research, there are still many PWID who do not utilise services and therefore may not be represented in the existing literature (Paquette, Bryant, & De Wit, 2012).

6.1.2 Recruitment

The social network recruited in South-East Sydney commenced through discussions with staff of a Sydney-based organisation which provides advocacy and support services for PWID. The key individual recruited to the study site has been allocated the pseudonym 'Henry'. Henry was recruited partly because he was at the service on the first scheduled day of data collection and also because he had participated in other research projects conducted by the researcher and therefore a rapport had already been established. Henry also participated in the pilot testing phase of the data collection process. During Henry's interview he identified three sub-groups that he socialised or injected with. Six social network members, including Henry, were recruited from the social network based in South-East Sydney. This process began with Henry personally contacting Kevin, who agreed to participate in the study after discussions with the researcher. When Kevin attended the interview, his partner, Catherine, who had accompanied him, was also recruited to the study and interviewed immediately after Kevin. Henry also recruited Toby and Alison to the study by asking them to make contact if interested, and both were subsequently interviewed after. When Alison attended the interview, she was accompanied by ex-partner Rebecca who was also recruited and interviewed immediately after Alison. Henry also identified another younger PWID sub-group that did not participate in the study, and these individuals have been allocated the names Stuart, Ben and Kyla. Henry explained that Stuart, Ben and Kyla were young, inexperienced in participating in research and unwilling to talk about drug use with a stranger. Kevin and Toby also spoke of a number of different social networks to which they belonged; however, these wider networks were not identified in any detail by either participant during the study interview nor recruited into the study by Kevin or Toby.

6.1.3 The main characters

The South-East Sydney network comprised at least ten individuals known to be socially inter-connected, six of whom participated in the study. Of those that participated, three lived in SES and three did not. The SES network members that did not live in South-East Sydney travelled to the area,

sometimes daily, to meet with friends, access sterile injecting equipment and purchase and consume drugs. Poly drug-use was common amongst all South-East Sydney network members, with their drugs of choice including cocaine, heroin, morphine, other pharmaceutical opiates, such as OxyContin, and methamphetamine, which is also known as ice. All South-East Sydney network members were unemployed and received unemployment benefits or a disability pension as their main source of income. Homelessness was a common concern among the younger members. All South-East Sydney members, except Henry, had completed at least four years of high school and obtained their School Certificate. All members self-reported as hepatitis C positive, and of those, one had undergone treatment in the past (which was unsuccessful) and one was undertaking hepatitis C treatment at the time of interview. All South-East Sydney network members, except Catherine, had previously participated in research studies.

Henry was a 22 year old Anglo-Australian male who lived in the South-East Sydney district. Henry started injecting at 12 years of age and left formal education after completing his third year of secondary school. Between the ages of 12 and 20, Henry identified as a heroin user and during this time he was homeless and moved frequently between Australian states and cities. Five months prior to interview, he enrolled in a methadone maintenance program and had found somewhat stable accommodation in South-East Sydney with Kevin and Catherine. At the time of interview, Henry's main source of income was unemployment benefits. He was injecting cocaine approximately once a fortnight and accessed his injecting equipment from a South-East Sydney NSP or through peer distribution. Although Henry had most commonly injected in public places in the past, he reported that he no longer did this and so would only inject in his home or the homes of his friends. Henry self-reported as hepatitis C positive and was considering hepatitis C treatment at the time of interview.

Kevin was a 48 year old Anglo-New Zealander male who lived in the South-East Sydney district, with his girlfriend Catherine and Henry. Kevin started injecting at 15 years of age. He had left formal education after completing his fifth year of secondary school, aged 17. At the time of interview, Kevin identified as a poly-drug user and injected daily. Kevin most commonly injected opiates (OxyContin) and methamphetamine (ice), although he would also inject speed, cocaine and a “little bit” of heroin. Kevin generally injected at his home but would also inject at the Medically Supervised Injecting Centre (MSIC) and homes of his friends. He accessed his injecting equipment from NSPs and pharmacies. Kevin’s main source of income was unemployment benefits. Kevin had been in a sexual relationship, and lived with, Catherine for five years. Kevin self-reported as hepatitis C positive. He had undertaken a course of hepatitis C treatment; however, the treatment did not produce a sustained virological response.

Catherine was a 33 year old Anglo-Australian female who lived in South-East Sydney. Catherine had left formal education after completing four years of secondary school, aged 16. Catherine started injecting at 19 years of age and at the time of interview, identified as a poly-drug user who injected daily. The drugs most commonly injected by Catherine were opiates (OxyContin) and speed. Although she had injected heroin in the past she reported that she no longer did so. Catherine only injected at home and with Kevin, and accessed her injecting equipment from NSPs and pharmacies. Catherine was receiving a disability pension at the time of interview, and was also prescribed buprenorphine for heroin dependence and another medication for schizophrenia. She self-reported as hepatitis C positive and at the time of interview was in her third week of a 48 week course of hepatitis C treatment.

Toby was a 22 year old Anglo-Australian male who did not live in the South-East Sydney area. Toby was homeless and travelled to South-East Sydney on a daily basis to source drugs and injecting equipment. He stored his clothes and other belongings at a friend’s house, about an hour and a half

away from Sydney. Toby left formal education after completing four years of secondary schooling, aged 16, and his main source of income was unemployment benefits. Toby started injecting heroin at 18 years of age and at the time of interview, injected once a day, usually in public places such as squats and public shooting galleries. Toby only identified cocaine use in his interview, however, Alison, Rebecca and Henry believed he was also injecting heroin. Toby accessed all his injecting equipment from NSPs and self-reported as hepatitis C positive.

Alison was a 27 year old Anglo-Australian female who did not live in South-East Sydney as she had moved from Queensland to a suburb in Sydney's inner-west four months prior to interview. Alison's main source of income was a disability pension and at the time of interview she lived with her ex-girlfriend, Rebecca, in Rebecca's brother's garage. These living arrangements provided constrained access to running water, toilet and kitchen facilities. Alison left formal education having completed her Higher School Certificate, aged 18. Alison started injecting at 18 years of age and at the time of interview injected opiates on a daily basis, including morphine, heroin and buprenorphine. Alison usually injected by herself, however when injecting with others she would do so with two male friends, one of whom was Toby. Alison accessed all her injecting equipment from pharmacies. Alison self-reported as hepatitis C positive.

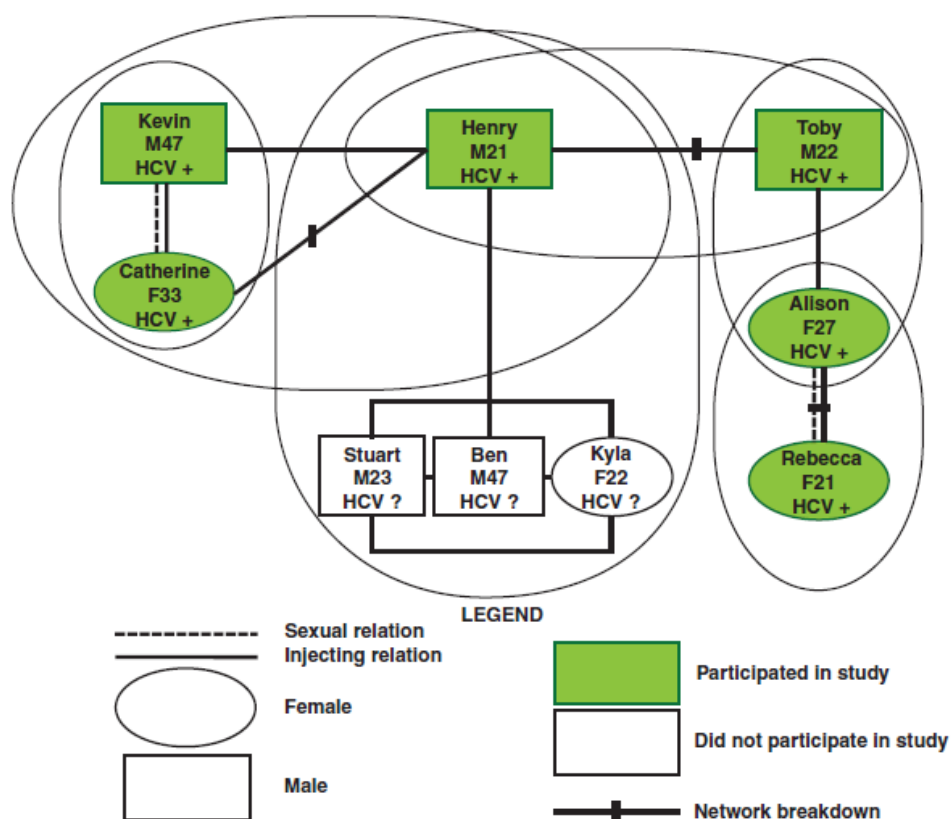
Rebecca was a 21 year old Anglo-Australian female who did not live in South-East Sydney as she had recently moved to Sydney and was living in her brother's garage with Alison (in inner western Sydney) at the time of interview. Rebecca had left formal education after four years of secondary school, aged 15. Her main source of income was unemployment benefits. Rebecca started injecting at 17 years of age, but had not injected for two to three months prior to interview after attending a live-in rehabilitation program. Prior to the rehabilitation program, Rebecca and Alison would inject morphine, heroin and speed on a daily basis. Most injecting episodes during this time were in public

places, such as parks and stairwells. When Rebecca was injecting she accessed her injecting equipment from Alison. Rebecca self-reported as hepatitis C positive.

6.1.4 The network relationships

The South-East Sydney network was comprised of at least five known sub-groups, which included both the individuals who took part in the study and others who chose not to participate but who were described through the accounts of participants. All known South-East Sydney network relationships have been diagrammatically represented in Diagram 3.

Diagram 3 South-East Sydney social network and sub-groups



The first sub-group included Kevin, Henry and Catherine. Since the beginning of this relationship, Catherine would only inject at home and only with Kevin. She did not speak of any other significant

social and injecting relationships. Kevin reported a large network of people that he interacted and injected with; however, he did not discuss or disclose those people or their relationships so as to maintain their privacy. The second sub-group included Henry, Kevin and Catherine. This sub-group had been formed approximately five months prior to interview when Henry began living with Kevin and Catherine. Henry and Kevin injected cocaine together and Catherine and Kevin injected opiates together. Henry and Catherine did not inject together.

Henry was also a member of another sub-group that only injected cocaine. This third sub-group, who were all of a similar age, included four current members and one person who had been a regular member but had been recently excluded from the sub-group. The network members included Henry, Ben who was 28 years old, Ben's girlfriend Kyla who was 22 years of age and Stuart who was 23 years old. Henry had met Ben and Stuart whilst in prison a number of years prior and was friends with the Kyla due to her relationship with Ben. With the exception of Henry, none of the sub-group members chose to participate in the study and the accounts presented in this chapter were therefore constructed through accounts provided by Henry. This sub-group had also previously included Toby (who did take part in the study); however, Toby had been excluded from the sub-group because of his heroin use.

Although Toby portrayed himself as someone that spent a fair amount of time on his own, as a bit of a 'loner', Toby did regularly travel to Sydney to inject and socialise with another unidentified 24 year old male, who did not participate in this study. Toby would also inject heroin with Alison, forming a fourth South-East Sydney network sub-group. This sub-group would only meet to pool resources in order to secure enough drugs for a shared injecting episode, but once this was completed they would go their separate ways. Alison and Rebecca form a fifth sub-group, however, since Rebecca had ceased injecting a few months prior to interview, this has to be viewed as a non-injecting sub-group of this social network of PWID.

6.2 Hepatitis C-related understandings

The following section will describe the South-East Sydney's network members' knowledge and beliefs about hepatitis C and hepatitis C treatment and consider the degree of concordance between these and accepted hepatitis C knowledge. This section will also investigate how these understandings seem to have been developed and shaped, including an exploration of the level of seriousness ascribed to hepatitis C.

6.2.1 Knowledge about hepatitis C

There was considerable range evident in the level of knowledge held by South-East Sydney network members regarding hepatitis C transmission and treatment. All network members were well aware at the time of interview of the transmission risk associated with needles and syringes, however, many reported a significant time delay between when they had started injecting and when they became aware and knowledgeable about hepatitis C. Additionally, the knowledge about, or prioritisation of, hepatitis C transmission from other injecting equipment and the injecting environment more generally was diverse. All South-East Sydney network members were aware that there was treatment available for hepatitis C; however, there appeared to be significant differences between the different network members with respect to their understandings of hepatitis C treatment. The rest of this section will explore how knowledge of hepatitis C transmission and treatment seem to have been developed, shaped and changed over time within this network, including discussion of the role of the social network itself in these processes.

Nearly all South-East Sydney network members described increases in their hepatitis C-related knowledge since they had first started injecting. For the younger network members, this was explained in terms of not being interested or not knowing to look for information. For example, as Henry explained:

When I first started using nobody really talked about [hepatitis C]. I didn't even really know that much about it to be honest. I don't think [hepatitis C] was really a talked about subject. Like don't get me wrong, there was pamphlets and all that stuff in the youth centres and shit like that but when you're that young you're not really interested. You're more interested in going out and having fun with your mates (Henry, M22).

Henry believed that his knowledge of hepatitis C had been limited by both a lack of discussion among PWID along with a lack of interest and willingness to become better informed, particularly at early stages of an injecting career. Henry's account highlights how being young or new to injecting drugs could mean that even engagement with services that do provide relevant information about important issues such as hepatitis C will not make a difference to increasing knowledge if service users are not interested. Henry has subsequently participated in a PWID peer education program where he learnt about the "different strains of Hepatitis. Type 1, 2, 3 and how that there's [hepatitis C genotypes] a, b and c. I also found out about the main ways of how [hepatitis C is] contracted, how it can also take up to six months to appear in the blood, stuff like that". Henry therefore seemed extremely knowledgeable about hepatitis C transmission and confidently communicated this throughout the interview, providing a stark contrast with the accounts of himself as a young injector with little interest in learning about harm reduction.

Henry also revealed that he was considering undergoing hepatitis C treatment and spoke about how he was monitoring his hepatitis C in preparation for that:

They [the health centre] know my genotype but I don't really ask. I just have a look at my LFTs [liver function test] and I just see how big my count is. Usually my counts only up in the hundreds so its ok (Henry, M22).

Although Henry identified genotypes in his account of hepatitis C, knew that hepatitis C treatment curative effects were different for different people and was considering hepatitis C treatment at the

time of interview, he was unaware of his own genotype. This was somewhat surprising as hepatitis C genotypes directly affect treatment duration and outcome. Given Henry's extensive knowledge of hepatitis C and the major changes he had made to his life in the lead up to a treatment regime, such as finding stable housing and entering a methadone maintenance program, it is unclear why Henry did not seek this information or whether he was actually aware of the impact of genotypes on treatment regimens and outcomes.

Alison also explained that she had not held any knowledge about hepatitis C at the beginning of her injecting career, she explained "[when I first started injecting] Not at all. We didn't learn anything at school about [hepatitis C] or nothing ... [I wish I had been told] how hard it would be and about all the diseases I guess, it would help". Alison interpreted the lack of knowledge she held early in her injecting career as resulting from not being provided with information about hepatitis C whilst at school, but then explained how her understanding had improved as a result of attending different PWID services. When Alison was asked what she wished she had been told at this time, she only talked in generalisations of how 'hard' it would be to have hepatitis C. Alison did not mention a need for information about safe injecting and other health-related issues, only those relating to the hepatitis C virus itself.

Alison's ex-girlfriend, Rebecca (F21), explained that she was aware of the different transmission routes of hepatitis C because Alison "got me some pamphlets and I went to [an NSP interstate] and just found about it". In this account, Rebecca's knowledge of hepatitis C transmission was represented as having been initially shaped in response to information she had come into contact with from Alison, suggesting this information was the catalyst for accessing an interstate-NSP to find out more about hepatitis C. However, in Rebecca's response there was little information provided about what hepatitis C transmission meant to her except for the perceived need to be 'cautious' and to not share injecting equipment, including filters and spoons, with Alison. Rebecca also explained

that she had not used services for PWID or general health care since she had moved from Brisbane to Sydney, making her reliant on Alison for information. When asked how she would come into contact with information about hepatitis C treatment, Rebecca explained:

How would I get information that's actually a good question? I'm still on the verge of like realising that I've got it so I still I care but not really you know and I should care a lot more than I do ... I'd like to [seek more information about hepatitis C treatment] but I just haven't got the right state of mind just yet (Rebecca, F21).

For Rebecca, a lack of engagement with information and services for people with hepatitis C was explained as only having recently testing positive and therefore not feeling in 'the right state of mind' to make decisions about treatment. Furthermore, as Alison was her primary source of information and Alison believed that hepatitis C had not affected her after eight years of infection, this may have also influenced Rebecca's willingness to engage with information and issues relating to hepatitis C treatment.

Toby also explained that he had not come into contact with information about hepatitis C transmission until at least a couple of years into his injecting career. He explained that "[I wish I had been told] simple things like you can catch [hepatitis C] from using your own [needle and syringe] over again or using a spoon". In Toby's account, we can see that even after coming into contact with hepatitis C-related information, a persistent misunderstanding was held regarding hepatitis C transmission, especially in relation to the transmission of hepatitis C from the re-use of one's own needle and syringe. Toby identified the hepatitis C transmission risk from spoons; however, he also explained in another part of the interview that he would reuse a spoon that he carried with him.

Although Toby was hepatitis C positive, he explained that he did not have any knowledge about hepatitis C treatment:

No [I do not know anything about hepatitis C treatment]. Don't have any [knowledge about hepatitis C treatment] ... I've been given brochures and stuff at the clinic like [the NSP] have provided me with numbers but I'm just too scared to ring them up. Pretty much every time I come in here [the NSP] it's after I get on when I just need a shot. If you want people to talk to me then it's bad timing but maybe after a shot (Toby, M22).

Although in the above example Toby had been provided with print-based information about hepatitis C treatment, he also explained that he did not know what hepatitis C treatment was or what it involved. This lack of knowledge was also compounded by an unwillingness to contact services because of fear, which was explained by Toby in terms of "disgust". This fear could also be influenced by a lack of trust that Toby has with health professionals, who he described as having "their heads stuck up their arse and they don't care about anyone else that's lower than them, looks down on the junkies and streeties". Toby also explained that he was typically unwilling to learn about hepatitis C treatment from the NSP service that he frequented because he was there to access sterile injecting equipment prior to an injecting episode, which was his only priority in those moments. Given that Toby expressed a considerable degree of shame and disgust about living with hepatitis C (see later section), did not frequent NSP services other than prior to an injecting episode and did not talk about hepatitis C or treatment with his peers, it is unlikely that he would come into contact with any more detailed or specific information about hepatitis C treatment.

Kevin explained that he was also unaware of hepatitis C at the beginning of his injecting career:

No I don't think so, from memory, no I hadn't heard anything about [hepatitis C], not much anyway. Well no, come to think of it, I must have been aware of it because well [I was] certainly aware of blood-borne diseases anyway because it was a big no, no you know ... So I was aware of that but [hepatitis C] certainly

wasn't talked about or I was nowhere near aware of any of that sort of stuff as I am now. You know [hepatitis C] just wasn't on the radar (Kevin, M48).

Although Kevin and Henry's experience of hepatitis C knowledge was similar early in their injecting careers, in that they both were unaware of hepatitis C, there was some difference in the reasons provided by these two participants for this lack of understanding. Kevin had started injecting 30 years prior to interview (1981), and hepatitis C was not isolated and identified until 1989 (Choo et al., 1989). Thus, while Henry's accounts of being unaware of hepatitis C in the early years of his injecting career also featured a lack of interest, this can be seen to also be influenced by the lack of understanding that operated at that time more generally about this particular blood borne virus. HIV was also not identified in Australia until 1982, suggesting that Kevin's account does connect these network participants across a vast range of experiences in the history of blood borne virus prevention and care in Australia.

As a result of coming into contact with hepatitis C-related information later in his injecting career, Kevin was aware that all injecting equipment, as well as the injecting environment, provided possible transmission routes for hepatitis C; however, in his accounts Kevin was more likely to explain transmission in terms of 'hygiene'. Kevin explained that "you sterilise everything and there are those who don't you know there are really some putrid people that don't cleanse". These strong emotions expressed by Kevin, when suggesting that all PWID should be vigilant about maintaining hygiene in the injecting environment, and by labelling those PWID who did not use adequate hygiene in the injecting environment as 'putrid': a clearly moralising statement in the context of an interview on injecting practices.

Like Kevin, Alison's hepatitis C knowledge had also changed over the course of her injecting career, and interestingly this knowledge change was also expressed in terms of hygiene narratives. Alison explained that "[hepatitis C is] just some blood borne virus and that you can get easily but not that

easy. Well I dunno, I don't reckon it's real easy. Well it is if you're not careful but yeah [Spoons] are carriers too". Like Kevin, Alison described the ease of transmission in terms of how 'careful' you were during an injecting episode, including managing the risk of blood being present in the injecting environment. However, Alison questioned her own account of the ease of hepatitis C transmission, changing her mind from transmission being easy to 'not that easy' and finally locating hepatitis C transmission in terms of cleanliness and care in the injecting environment: indicating that Alison's account was not stable and may therefore be more easily influenced by others.

Kevin's partner, Catherine, understood that hepatitis C was a blood-borne virus and that transmission could occur through the sharing of injecting equipment. Within her account of hepatitis C, Catherine also understood the impact of hepatitis C on the liver and the curative potential of treatment. She explained: "Yeah I know how [hepatitis C] affects the liver and it's a curable blood-borne disease". However, Catherine provided no detailed information about her knowledge about hepatitis C transmission during the interview. Catherine was also in her third week of a hepatitis C treatment regime at the time of interview and she explained how her knowledge of hepatitis C treatment had changed over time: "No I wasn't sure [that there was a treatment for hepatitis C] until the last five or six years. [It was] when I went to rehab that I became aware that there were vaccinations and preventions. I thought pretty much once you got it, that's it, it's over and there's nothing anyone could do so I was surprised". For Catherine, her previous misconceptions about hepatitis C treatment were challenged as Kevin had not experienced any significant side-effects from his hepatitis C treatment regime and this appeared to have influenced Catherine's own increased openness to treatment.

6.2.2 Beliefs about the seriousness of hepatitis C

All South-East Sydney network members were asked whether they believed hepatitis C was serious and viewed as a priority, and their various ways of thinking about this have been organised into

three thematic categories: comparing the seriousness of hepatitis C to HIV; hepatitis C as serious; and underestimating the seriousness of hepatitis C.

Henry, Toby and Catherine believed that hepatitis C was serious, but this was typically expressed in relation to the perceived greater degree of seriousness of HIV. As Henry explained:

HIV among drug users is called 'the dreaded'. If you know someone who is HIV, they're stigmatised. They're not the type of person that anyone really uses with. There's a stigma attached with that, hell yes. But the hep C not as much in the inner-city because pretty much everyone that's IV drug user is pretty much got hep C ... I wouldn't say [hepatitis C is] part of a drug user's identity but it seems to be one of the things that's associated with drug users (Henry, M22).

Henry's perception of HIV as being more serious than hepatitis C was expressed in terms of the particular and persistent fear and stigma associated with HIV among networks of PWID, including the potential for a HIV positive disclosure to result in exclusion from injecting based social networks. In contrast, Henry explained that hepatitis C was not perceived to be as serious, and he believed this was because hepatitis C was far more ubiquitous amongst PWID populations. This view was not voiced by other South-East Sydney network members.

Toby expressed disgust about the topic of hepatitis C by stating that he believed that hepatitis C represented a disease on a continuum with HIV:

It's disgusting, it's just dirty. It's a step towards HIV ... 'Cos I've got it [and it makes me feel] disgusting, terrible. 'Cos there's heaps of people with hep C that all fucking feel like me and feel like their life's over (Toby, M22).

Toby's description of hepatitis C being a progressive step towards HIV is unique because he not only prioritises HIV over hepatitis C, he also makes a conceptual link between the two viruses. Although Toby perceived HIV in this instance to be more serious, hepatitis C was also viewed as extremely

serious, partly because of this view of hepatitis C as a 'step towards HIV'. Toby's description of the emotions he associated with hepatitis C were extreme in comparison with the rest of the South-East Sydney network, however Toby also explained that he believed many people felt the same. Like Toby, Catherine also explained her beliefs about hepatitis C through a comparison with HIV/AIDS:

Yeah I've thought a few times you know because that [hepatitis C is] an STD, classed as an STD. That it is as bad as AIDS and I think I will have a longer life span than I first imagined when I set out about 18. I would have thought [hepatitis C] killed you but it turns out it doesn't kill you straight away and the Interferon should help ... No hepatitis C is not a priority, not really. I don't think really think about it (Catherine, F33).

Catherine was the only network member who made a link between hepatitis C and sexually transmitted diseases (STD), although little was discussed in relation to this understanding. Like Toby and Henry, Catherine's perception of the seriousness of hepatitis C had been initially based on a belief that both hepatitis C and HIV could be fatal; however, her perception had changed as a result of coming into contact with information about the natural history of hepatitis C and current treatment options. However, Catherine's closing statement that hepatitis C was not something she thought about or a priority is surprising considering she was undergoing a course of hepatitis C treatment at the time of interview. Nor did her perception of the seriousness of hepatitis C when compared to HIV reflect that of her partner Kevin.

Kevin was the only South-East Sydney network member that viewed hepatitis C as a more serious concern than HIV:

[Hepatitis C is] very serious yeah. I believe it's, from what I've heard, it's more serious than HIV. There's more people infected with hep C and probably in the long run there's more people gonna be seriously affected and die from liver disease than HIV you know yeah. In the Western countries anyway ... Well it's

more widely spread than a lot of people are aware of I think and you know unless people clean up their acts, which I don't know what the statistics show, but for people to be keep getting infected, you know, new infections, it appears that hep C is gonna be around for a long time (Kevin, M48).

Kevin's belief that hepatitis C is more serious than HIV diverged markedly from that of the other South-East Sydney network members. Kevin explained his views on the seriousness of hepatitis C by referring to the large numbers of people infected with hepatitis C in comparison to HIV, high rates of new hepatitis C infections, the long term effects of chronic hepatitis C, such as liver disease and the possibility of death. This assessment of seriousness may have been influenced by Kevin's unsuccessful attempt to clear the virus through treatment. Interestingly, none of the issues identified by Kevin were reflected in Catherine's or Henry's account of the seriousness of hepatitis C, which may also allude to a lack of hepatitis C-related discussion between them.

Both Alison and Rebecca explained that they believed hepatitis C was serious, although they had different reasons for understanding why the seriousness of hepatitis C may be underestimated. Alison explained: "I think it [hepatitis C] is [serious] you know like when it starts to take a toll on you but I don't know. I've had it for about eight [years] or something now and I dunno". In Alison's account, a lack of noticeable health effects after eight years of living with hepatitis C directly influenced how she perceived its seriousness. This belief may also explain her lack of engagement with hepatitis C treatment. Rebecca also explained that she believed that hepatitis C was serious but that the seriousness of hepatitis C had only been recently realised:

I didn't really think [hepatitis C] was that serious and [Alison] was trying to tell me that it was. But you know, now that I've got it I know that I should have cared more. Yeah I wish I knew the seriousness of it. I wish I did think about it and realise the seriousness of it: but now that I've got it, it's too late (Rebecca, F21).

Rebecca's account of the seriousness of hepatitis C was expressed as guilt about not having previously cared enough about hepatitis C. It is unclear from her account whether Alison did not explain the seriousness of hepatitis C adequately to Rebecca or if Rebecca chose not to listen to Alison's explanation. In either case, Rebecca viewed the outcome of that perception as having acquired hepatitis C: "now that I've got it, it's too late".

6.3 Hepatitis C-related communication

This section examines hepatitis C-related communication within the South-East Sydney network, including what network members discussed or did not discuss with others in the network. These various aspects of hepatitis C-related communication have been organised into four thematic categories: absence of hepatitis C-related discussions, discussing hepatitis C in terms of generalisations, specific and detailed discussions surrounding specific issues related to hepatitis C and disclosure of hepatitis C antibody status. Due to the relative absence of hepatitis C-related discussions or discussions only based on generalisations, further questions were posed to South-East Sydney network members in relation to what they thought should be discussed in relation to hepatitis C.

6.3.1 Absence of hepatitis C discussions

Although the South-East Sydney network were more likely than the other networks to discuss hepatitis C, an absence of hepatitis C-related discussions was still marked among the sub-group of Toby, Rebecca and Alison. This absence was most prominent in Toby's accounts, in which he spoke in very strong terms about the possibility of discussing hepatitis C:

I don't know [what would make me talk about hepatitis C]. I don't like it, it's [hepatitis C] disgusting. I hate talking about it, maybe for people in the future to learn so they didn't catch it like me or something. It's a bit of a silly question, what

would make me want to talk about hep C? Nothing, I'm ashamed of it. I don't talk about it (Toby, M22).

Although Toby suggested that people needed to talk about hepatitis C in order to prevent transmission, he seems here to feel genuine horror or disgust about engaging in such discussions. This disgust is likely to have directly influenced his capacity or willingness to talk about hepatitis C, even within a research interview. Within Toby's account a number of important issues that influence the absence (or avoidance) of hepatitis C-related discussion become evident, including judging himself for coming into contact with hepatitis C, which he perceived as shameful. These issues may give some insight into the extreme barriers Toby faced in initiating or talking about hepatitis C with his peers.

When Toby was asked what he did talk about with his network members, he explained:

We talk about getting money, getting on and then we don't see each other
... We get on, we have a shot and then everyone goes their own ways and
sees each other the next day. It's the same shit, different score (Toby M22).

Taking Toby's statement at face value, there was not much that could be described as 'social' in his engagement with this social network, outside of the pragmatic activities associated with purchasing and consuming drugs together. Whether or not this captures the full experience of all social network members, it is important to recognise the kind of utilitarian ethic that might operate in these contexts, reducing the need for and capacity to discuss other issues, particularly those relating to health and wellbeing.

An absence of hepatitis C-related discussions was also described by Alison, who was not aware of a time when she had been involved in or witnessed any hepatitis C-related conversations since she had moved to Sydney. Alison explained that she had also not discussed hepatitis C with Toby, nor was she aware of Toby's hepatitis C status. I asked Alison what she thought Toby would do if she had initiated a hepatitis C discussion with him. Alison explained "I dunno. I don't think [Toby] would

be very interesting to talk to”. In Alison’s response, rather than describing how she thought Toby would react, she chose to instead focus on her lack of interest in any of the opinions that Toby might hold, including information about hepatitis C. When Alison was asked what she would discuss with others with respect to drug use, she explained:

Sometimes we have discussions about what we reckon they should do and you know that they should get more places that you can inject in without getting into trouble and stuff like that so you’re not on the street all the time doing it and getting you know, police everywhere (Alison, F27).

For Alison, discussions were more likely to occur with respect to safe places to inject, and the structural and policing aspects of injecting in public places. Again, it is important to recognise the kind of utilitarian ethic that might operate in these contexts, whereby even general discussions between people with weak relationship ties were not readily recalled. Rebecca also explained that although she had had hepatitis C discussions with Alison, these conversations had only occurred at the beginning of their relationship and not with others, such as between Rebecca and Toby. As Rebecca explained, “I would talk about [hepatitis C] with her [Alison] but not [Toby], no way”. This absence of hepatitis C-related conversations between Rebecca and Toby may well be explained by similar reasons to those expressed by Alison, where there was no interest in having hepatitis C-related discussions with Toby. Alternatively, it could also be that Rebecca had not injected for a number of months and therefore had had little or no social contact with Toby during that time. It does also reveal, however, that making social connections with other people who inject drugs does not always mean you have to like or trust those people, which will influence the topics of conversation explored.

Kevin explained that, from his perspective, he felt able to talk freely and openly about hepatitis C with his peers because he was immersed within a drug using lifestyle and community:

Yeah, we all talk about it [hepatitis C] yeah ... See I'm so ingrained in this lifestyle now that everybody I know is connected with drugs in one form or another you know ... We all talk pretty freely about anything and everything you know like what's going on in the news you know, especially about the police presence, what's going on where, like who's been raided recently and who to stay away from and that sort of thing yeah (Kevin, M48).

Although Kevin asserted that discussion about hepatitis C was open within social networks of PWID, he did not provide any detailed examples of these kinds of discussions. In addition, when reflecting on the hepatitis C-related discussions that Kevin had with his peers, he explained that, like Alison, issues of policing and other structural risks were more likely to be discussed and recalled in far more detail. It is interesting to note the stark differences in the accounts of Kevin and Toby regarding hepatitis C communication in this network of PWID. Clearly, different people can have different experiences of social connections and will also construct different narrative accounts of those connections.

6.3.3 Discussing specific or detailed issues related to hepatitis C

The South-East Sydney network was more likely than other networks reported in this study to recall discussions about hepatitis C treatment, which may have been influenced by the positive hepatitis C status of all South-East Sydney network; all members of the Newcastle network self-reported a hepatitis C negative status and only two of the six South-West Sydney network members identified as hepatitis C positive. For example, Kevin and Catherine explained that because they had been exposed to different hepatitis C genotypes and were living and injecting together, they had occasional discussions of genotype re-infection:

Yeah we do talk about [hepatitis C] occasionally. Like the problems we'll have if our hep C's start breeding and cross contaminating. That we could have problems but we've both been down to hospital and that hasn't happened definite. Yeah

we've got different hep C type and Kevin has spoken about the danger of them cross occurring and becoming something worse but luckily that hasn't happened so we're keeping pretty clean (Catherine, F33).

For Catherine, the danger of contracting different hepatitis C genotypes had been discussed between herself and Kevin. However, the account provided by Catherine highlighted how she was somewhat reliant on Kevin's knowledge and experience about the issue and raises questions about whether, if Catherine was not in a relationship with Kevin, she have come into contact with this information? Further, Catherine's account also highlighted how generalised notions of hygiene, such as keeping clean, could be incorrectly believed to be effective in preventing hepatitis C genotype reinfection.

Although Henry and Kevin did not remember recently discussing hepatitis C transmission, Henry explained that he had had conversations with Kevin about hepatitis C treatment in the past:

[Hepatitis C] gets brought up every once in a while but not very often. Like if a friend of mine, he's starting treatment. Or [we would talk] if a friend whose going to consider starting treatment or if we read something in [local NSP] or something in the Users News (magazine) about something involving their treatments that might get brought up but most of the time we just talking about what's happening (Henry, M22).

In the example above, the person Henry was referring to was not identified during the interview, however, the focus on treatment conversations between Henry and his friends is not surprising considering that Kevin's girlfriend, Catherine, had recently started treatment and Kevin and Henry were in the process of considering their hepatitis C treatment options. However, as Henry and Kevin were injecting together, conversations about genotype reinfection, such as the ones Kevin had with Catherine, may have also been useful but do not seem to have occurred between Henry and Kevin.

Rebecca explained that she had also had discussions about hepatitis C treatment, although somewhat surprisingly these conversations were with her brother, who did not use drugs:

Well when they [Rebecca's brother and his girlfriend] found out I had hep C they weren't very happy and they wanted me to get the vaccination for it. I told them what would happen like I'd be sick for a year and I wouldn't be able to go to school and you know and they're complaining, they're telling me about Alison you know staying in bed all day 'cos she's sick. I told them I'm going to be worse than her if I get [treatment] and I'm not going to be able to go to school for a whole year and not be able to do anything for a whole year, won't be able to get my own place (Rebecca, F21).

Rebecca's account suggests that she may have had read information or had discussions with someone else about hepatitis C treatment, as she had a sense of treatment length and possible side effects. However, the conversation about this with her brother was not open and supportive; rather she quite actively tried to counter the possibility of undergoing treatment. It also appears from Rebecca's account that she had not had any hepatitis C treatment discussions with Alison. Again this absence may have been influenced by Alison's perception that hepatitis C was not going to affect her in the short-term, and so she had little interest in pursuing treatment.

Although not reported by Toby, Henry described a time when he and Toby had had a conversation about hepatitis C genotypes:

Yeah Toby actually [has talked about hepatitis C]. When he first started hanging around he used to lie all the time because he didn't understand. He thought that if he bullshit people they will think that he knows something and I eventually got sick and tired of saying 'you're wrong' all the fucking time. [For example he said] "Like there are nine different types of hep C" ... He first thought that you could get

hep C by kissing someone and stuff like that and [I said] “what you’re kidding me aren’t you?” (Henry, M22).

Henry’s questioning of facts communicated by Toby about hepatitis C may have directly influenced Toby’s willingness to subsequently initiate or discuss hepatitis C with others. Although the above example points to the presence of some hepatitis C-related information, it may actually be more significant as an example of how discussions around hepatitis C can be silenced within a social network when they are based upon the assertion and rejection of certain truths. Furthermore, when Toby was asked how he would respond to Henry if Henry initiated another conversation about hepatitis C, Toby explained that no one would listen and that he would “tell him [Henry] to shut up” because he “didn’t want to hear about it”. It is unclear whether telling someone to ‘shut up’ was the result of being challenged in the past. However, this response, coupled with feelings of shame and disgust in relation to hepatitis C, pose extremely significant barriers for Toby in initiating or contributing to hepatitis C discussions in the future.

Although Henry did not recall having detailed discussions with others about hepatitis C genotypes, he wanted to communicate his knowledge about this issue during the interview:

We’re lucky in a sense ‘cos we only have [hepatitis C genotype] type 1A over here ... Like India or Pakistan where there’s 3 types I’ve heard. And a, b and c are over there as well is you’ve got one person can have each individual genotype a well (Henry, M22).

Henry positioned himself as extremely knowledgeable about hepatitis C, including through his knowledge of the prevalence of different hepatitis C genotypes in different countries. However, Henry’s account did not include the knowledge that in Australia there are many hepatitis C genotypes, including those most prevalent in India and Pakistan. This raises the question, if Henry was challenged about the authenticity or accuracy of his information with respect to genotype prevalence in Australia, as he did with Toby (noted earlier in the chapter), would this result in Henry

not wanting to engage in discussions with others and hence create further silence around and limit discussions of about hepatitis C?

Although silence surrounding hepatitis C was identified by all networks reported in this study, most network members from South-East Sydney believed that if hepatitis C-related conversations were approached and discussed in terms of generalisations, these conversations were more likely to be permitted. These generalisations were most prominent when hepatitis C discussions were conceptualised through hygiene narratives, a finding also commonly reported in the literature (Rhodes, Kuneski, & Bernays, 2008; Rhodes & Treloar, 2008). Examples from this study include Rebecca describing the “need to be clean and careful” to avoid hepatitis C transmission and Henry drawing on hygiene narratives to determine who he would have discussions with, where there is no need to discuss hepatitis C with another because they were perceived to be a “clean user”.

Hygiene narratives had also woven themselves into the way that people in sexual relationships reported negotiating hepatitis C transmission risk. For example, Catherine described how she and Kevin engaged in ‘clean’ injecting practices to avoid genotype cross contamination. However, constructing something as clean frames alternative practices as “unclean”. In this study, examples of ‘unclean’ practices were those described as “dirty” (Toby) and “putrid” (Kevin). Although discussing hepatitis C in terms of generalisations was evident across all networks, the particular reliance on generalisations in the South-East Sydney network may have been influenced by a number of network characteristics, such as their longer average length of injecting histories, which is likely to have meant that those in South-East Sydney had more experience with negotiating the complex social cues that silence hepatitis C communication within networks of PWID.

6.3.2 Disclosure of hepatitis C antibody status

Within the South-East Sydney network, discussions about hepatitis C antibody status were most likely to occur between those network members who had close relationships with each other. However, disclosure across network sub-groups did not appear to occur.

There were a range of experiences described by South-East Sydney members regarding the disclosure of a hepatitis C positive status. For example, earlier, Henry described an absence of hepatitis C-related discussions at the start of his injecting career. Four years later, Henry suggested that this had changed and that he had personally begun to initiate hepatitis C-related discussions with his younger network, including the disclosure of his own hepatitis C status:

[There is no hepatitis C stigma] in the inner-city because pretty much everyone that's [an] IV drug user is pretty much got hep C. Like when I first explained to my boys that I had hep C, the people that were using were like 'so fucking what, everyone's got hep C' (Henry, M22).

Henry believed that hepatitis C-related stigma was not common in PWID networks in the inner-city due to a perceived normalisation of this condition. As a result of this belief, Henry felt comfortable to disclose his own positive hepatitis C status to his cocaine injecting sub-group. These discussions may be particularly important in an environment where hepatitis C is rarely discussed because they may provide information that otherwise would be unavailable to young PWID. Additionally, the willingness of Henry to disclose his status to this sub-group, – who Henry called 'my boys' and who were younger than him and did not have extensive injecting histories compared with Henry's other injecting sub-groups – may also serve to reduce the sense of these discussions being unacceptable within networks of PWID. However, the ease with which Henry described disclosing his positive hepatitis C status was not evident in the accounts of other South-East Sydney network members. Interestingly, although Henry may have believed that hepatitis C was ubiquitous and not

stigmatised in networks of PWID, there were still instances observed through interviews in which some of his younger network members had not disclosed their hepatitis C status to Henry, resulting in a one-way discussion between Henry and his younger peers:

He's non hep C but I don't really bring that up with him you know what I mean.

There could be a possibility that he might have, but he's a very clean user. [I would probably initiate a hepatitis C discussion] if he was looking a bit yellow or something like that I'd ask him how he is, we don't really bring that up most of the time. But if somebody in the group is feeling sick he might talk to me about that (Henry, M22).

The above example highlights how Henry at some point in time has made a decision about who he would discuss hepatitis C. In this example, being a 'clean user' was not perceived as necessary to initiate hepatitis C discussions. Furthermore, Henry also made assumptions about other people's hepatitis C status, without a discussion or disclosure having actually taken place. When disclosure had not occurred, Henry's initiation of these discussions would be based on his perception of another person looking jaundiced, or yellow, and yet this is not a common symptom of hepatitis C.

Although Kevin asserted that he would have open discussions about hepatitis C, he also suggested he would be quite selective about whom he would disclose his own status to:

I like my privacy you know. I don't want everyone, like I don't tell everyone I got hepatitis C you know. Like it's, there's a stigma attached to it, I don't tell everyone that I use drugs and that you know. So that sort of thing, privacy (Kevin, M48).

This selective nature of disclosure further highlights how hepatitis C communication can be directly influenced by the stigma attached to the virus within networks of PWID. Given that Kevin had previously suggested that hepatitis C was more serious than HIV and that he talked about other issues with his peers freely, the fact that disclosure of a hepatitis C infection was a selective topic of discussion for a man who was seen to have influence within his network suggests that the

constraints on disclosing a hepatitis C infection within networks of PWID are significant. Additionally, the example also highlights how people who believe they have the ability to assert authority in network settings, such as Kevin believed he did, also meant that Kevin positioned himself in control of the nature of network-based communication. In the above example Kevin choose to not talk about hepatitis C for a range of reasons, however, this lack of discussion was seen to protect others and therefore Kevin may be acknowledging the barriers to discussing hepatitis C in these network settings, whilst also positioning himself as the go-to person if his friends wanted to talk. Interestingly, Kevin's authority was not explicitly voiced by other network members, except his partner Catherine. The ability and willingness of influential people, such as Kevin, to initiate or discuss hepatitis C with others could offer a critical entry point into facilitating more open conversations about transmission, prevention and treatment issues. However, these discussions will continue to face significant barriers until the stigma of hepatitis C is reduced.

Alison and Rebecca both reported having disclosed their hepatitis C status to each other, however, this conversation was a one off and had only occurred at the beginning of Rebecca's injecting career. Given the lack of hepatitis C-related discussion recalled by Rebecca, I asked her how she thought you could get young people to talk about hepatitis C. Rebecca explained:

Like we can try [to get young people to talk about hepatitis C]. I don't know if it's going to get through to them ... Yeah and you just want to fit in yeah you do stuff just to fit in and I think that was my problem like I just wanted to fit in. [I would tell other young PWID], yeah, like, be careful. You know you can never know. I'm an example. I don't know how I caught it. So you never know how you can catch it (Rebecca, F21).

Rebecca suggested that although you could try to talk to young people about hepatitis C, social issues such as "fitting in" made initiating these discussions difficult. Rebecca's account suggests that the desire to feel included and form part of a peer group may create a barrier for young people to

talk about hepatitis C. Further, Rebecca highlighted how hepatitis C discussions, even hypothetical discussions or messages to provide people with in the future, can be constrained by the tendency to make generalisations about hepatitis C. These generalisations, such as being careful and being clean, may help to overcome some of the structural and social barriers of discussing hepatitis C, however, these same generalisations may also work to maintain the silence about specific details of hepatitis C transmission and prevention.

6.4 Social network dynamics in the injecting environment

The following section will explore the social network dynamics that shaped injecting practices within this network. This will include an analysis of the practices and rules that were followed in injecting settings, such as injecting hierarchies, always using sterile injecting equipment and the impact on individuals when network relationships were negatively impacted or broke down. This section will also analyse why these social network dynamics may have occurred and how they may have influenced hepatitis C transmission risk within this specific network setting.

6.4.1 Injecting roles and hierarchies

All South-East Sydney network members, with the exception of Catherine and Kevin, spoke about specific injecting hierarchies within their immediate network sub-groups. For example, when Rebecca and Alison were injecting together, Alison would take responsibility for preparing the drugs and injecting both herself and Rebecca. Rebecca explained that this was because Alison was 'more experienced'. In addition, Alison was responsible for ensuring access to sterile injecting equipment, which she accessed from pharmacies in the South-East Sydney area. Alison's ownership of the practices of sourcing and preparing drugs and providing access to sterile injecting equipment created an injecting hierarchy which potentially placed Rebecca at higher risk of hepatitis C transmission. This increased risk was the result of a number of factors, including being injected by another person, being injected second and because the injecting episode usually occurred in a public place. As both

Rebecca and Alison had contracted hepatitis C, the higher risk would only be an issue if they had contracted different hepatitis C genotypes.

When Alison and Toby injected together, Toby would source the drugs, and this resulted in him also preparing the drugs. During an injecting episode, the drugs were usually prepared in one spoon that was carried at all times by Toby, and then both Alison and Toby would draw the drug solution up from the spoon into their syringes. As Toby explained:

All the time I mix up ... [I] take it all out of the bags and put it all on a spoon ...

Yeah pretty much I just take what I want and give them what's left. It's pretty nice

'cos I always mix up ... I mix up, 'cos I'm the oldest. Well I'm just the toughest. I

don't know they always look up to me. This gronk [unidentified male 24 years] is

fucked [he] puts too much water with it. He just does whatever I do. [When

injecting with] Alison, I mix up. She usually goes second after me, 'cos I have to

hold her arm [because] her arms [are] just thrashed now. (Toby, M22).

Toby's perception that others in the network looked up to him because he was the 'toughest' and the 'oldest' and that he knew how to prepare drugs more effectively was not voiced by other network members. Toby believed that age, attitude and experience justified his position at the top of an injection hierarchy and engendered a level of respect from others. Toby also explained that when he injects with Alison, he always injected first because he had to then assist Alison to inject due to vein damage, which involved holding Alison's arm during her injection event. This practice was not noted in Alison's account, but may be the result of Alison not wanting to appear less experienced or unable to inject herself in the research process.

Conversely, Alison explained that during an injecting episode that involved Toby, he would prepare the drugs because he was the one to source the drugs. Alison also explained that the first to inject would be the person who would draw the solution from the spoon up into their needle the quickest.

However, Alison did not perceive the injecting environment to be as clear cut as Toby, describing the situation as 'complicated'. When asked why, Alison explained: "well there's so much that surrounds using drugs. Like, you just don't use drugs. It comes with all this other crap as well and ends up making it pretty complicated". Although Alison was not explicit in what this 'other crap' was, her responses to other questions suggest that at least some of that 'other crap' might have included having to inject in public places, having to make sure she could access sterile injecting equipment when required and having to travel to the inner-city to combine resources with other network members to purchase drugs. Furthermore, Alison's low position in an injection hierarchy, with others typically preparing her drugs, also she had little control over the equipment used in the preparation process. Another important influence in this injecting hierarchy was the need to conceal her current drug use from Rebecca and the other people living in her house.

When Henry described the process leading up to and including an injecting episode with his younger network, each individual had a specific role to play within the drug sourcing and preparation processes:

She's sort of like the house; she's the provider of an establishment pretty much.
[Her boyfriend is] a worker, he actually works Monday to Friday ... he provides more finances in the group ... [The preparation of drugs] most of the time it's me but if [others pay] they'll mix up. Like with us guys whatever's ours we give you know what I mean like it doesn't matter if its pot, if its alcohol or food doesn't matter, nine out of 10 times if its alcohol or food whatever 9 out of 10 times we just give what we got the only one that itches about that is [the female member] believe it or not (Henry, M22).

A particular moral economy is described in this account, including specific roles and the mutual sharing of resources, food and drugs, and these form important social network dynamics within the younger of Henry's two sub-groups. Henry described sourcing the drugs, Kyla (F22) providing the

house to consume their drugs and her boyfriend, Ben (M28), often providing the finances. Although Henry stated that whoever paid for the drugs was typically responsible for preparing them, this role appeared to be less defined among this sub-group. The issue of network role may also allude to another reason why Toby was excluded from this group, as Toby had no role or resources to add to, or complement, the sub-group. Although identified as roles, these aspects of the processes leading up to and including the injecting episode may also have the ability to influence the injecting hierarchies within Henry's younger sub-group.

Interestingly, Kevin and Catherine both chose to not describe their injecting practice with any detail, including the practices they engaged in to source, prepare and inject their drugs, when they injected together. However, both were happy to discuss injecting practice with respect to Catherine and her previous partner. As Catherine's partner did not participate in this study and the relationship occurred over five years in the past, aspects related to injecting practice in Catherine's previous relationship have not been reported or analysed in any detail in this study. However, immediate differences between the two relationships, and their influence on hepatitis C risk, were evident between the two relationships: where Catherine's historical relationship was one described as abusive and controlling, where as her relationships with Kevin was described as loving and supporting.

6.4.2 Always using sterile injecting equipment

All South-East Sydney network members identified the need to ensure that they had sterile injecting equipment for every injecting episode and in most instances, having sterile injecting equipment was a formal rule that, if broken, had serious consequences for continued participation in the network. However, the social network roles and dynamics, together with the physical location of injecting, strongly influenced the ability of South-East Sydney network members to access and have available sterile injecting equipment when required.

Henry explained that he had a rule of always using sterile injecting equipment within his younger network, something he described as “always a big policy”. However, Henry was not asked what would occur if someone found themselves in an injecting episode and did not have sterile injecting equipment. Catherine described a rule she followed of only injecting at home with Kevin. Catherine explained that they both felt they had a mutual responsibility to ensure that there was sterile injecting equipment available. Neither could remember a time where there had not been sterile equipment available in their home, as it was accessed through a relatively easy trip to the pharmacy or NSP. Given that Kevin collected more than 200 needles and syringes weekly (see Chapter 7: Peer Distribution), they both explained that it was not likely that they would be in a situation where they did not have access to sterile injecting equipment. As Catherine was the only network member, besides her partner Kevin, who indicated that they had never been without sterile injecting equipment when needed, Catherine was asked hypothetically what would happen if they did not have access to sterile injecting equipment, she explained “we’d have to go without [injecting] and my boyfriend would have nothing and I’d have a smoke but he doesn’t smoke”.

Kevin explained that that rule of always using sterile injecting equipment was generalised beyond his intimate relationship with Catherine in that it also applied to other people when they came to his house to inject:

I’m sort of quite well respected in our circle, sort of thing, and people listen to me and yeah. [I would tell them] just to be, like don’t share needles and shit like that you know. And if you’re gonna use, if you can’t get a clean needle make sure you give it a good clean with bleach or something. Don’t just rinse it with water and that (Kevin, M48).

As a result of the respect Kevin believed he had earned with members of his hidden network, who included a number of unnamed PWID who would visit Kevin’s house daily to inject, he felt able to

vocalise the need to always use sterile injecting equipment or appropriate cleaning techniques, such as bleaching, when having to reuse equipment. Alongside this advice, Kevin also provided access to sterile injecting equipment so that his friends could put his advice about safe injecting into practice when injecting at Kevin's house. The provision of sterile injecting equipment and information about safe injecting practice could be seen to influence the prevention of hepatitis C within this network setting. This example also highlights how Kevin positioned himself as influential and credible within this particular network setting. This credibility could be used to promote harm reduction and deliver peer education in network settings, however, an individual's authority and credibility within a social network is also complex and will be influenced by a range of network dynamics that could influence the nature and delivery of hepatitis C peer education messages.

Toby confrontationally and aggressively discussed the rule of not having used equipment in an injecting episode where he was present. Toby explained that if a person did not have their own sterile injecting equipment, they would not be able to inject with him and would have to go elsewhere. Toby explained "Yeah I'd be kicking him in the teeth. That's disgusting. I wouldn't let him use with us I'd tell him to go and get himself some clean shit or go use yourself". Although Toby explained that he expected others to always have sterile injecting equipment and the extraordinary lengths that he would go to if people did not, Toby may have prioritised his concerns about needles and syringes at the expense of other injecting equipment, such as spoons. This was indicated when Toby claimed that he would always use the same spoon in all injecting episodes, which may or may not have been cleaned adequately. It is not clear why Toby did not think that the reuse of his spoon was also an instance of injecting equipment reuse when he was aware that spoons could transmit hepatitis C. Furthermore, as finances were usually shared when purchasing drugs in Toby's network sub-groups, it is questionable whether he would actually have the ability to enforce exclusion based on a person's used needle and syringe. As there were no instances recalled by Toby of using violence

or excluding someone from an injecting episode it is more likely that Toby was interested mostly in portraying himself as 'tough' during the interview.

The only South-East Sydney network member that spoke of personal reuse of injecting equipment was Alison:

Yeah, I used to keep the spoon in the bottom of my bag and it would go rusty and I'd still use it and people would be like 'don't use that it's all rusty' and I ended up getting sick from it too so. I didn't listen because I thought I knew better as you do when you're off your head you think you know the best and you don't (Alison, F27).

Alison's quote is interesting because although other people had told her about the risk of reusing a spoon and her experience of having a dirty shot and getting sick, Alison's response highlighted how she would not always take advice from others or was not open to listening to information about safe injecting practice because she thought that she knew best. Obviously Alison is constructing this account retrospectively, and is aware that this belief was erroneous, due to her subsequent experiences. However, it nonetheless provides an interesting insight into the persistence of individual routines and preferences regarding injecting practice, which may not always be amenable to social norms and peer influences.

6.4.3 The breakdown of network relationships

Network relationships, especially where network relationships involved conflict or broke down, can have a significant influence on hepatitis C transmission risk. Kevin explained how the trust between network members had gone through periods of challenge and transformation, specifically referring to an incident he had with Henry.

[Henry] owed me some money for a while but that was pretty silly and he avoided me and he didn't have to you know. Friendship overrides all that yeah. (Kevin, M48).

We can see here that Kevin believed that Henry had avoided him because of money owed and while this avoidance was not described in Henry's interview, it would have had a number of implications that could be seen to influence hepatitis C transmission. For example, if Henry had been avoiding Kevin he would not have been living at Kevin's house and this would have had implications for where Henry injected and who he injected with.

In a more extreme example of social network breakdown, Henry described how Toby had been injecting with another sub-group and how those connections were seen to increase Toby's risk of acquiring hepatitis C:

Like our mate Toby, when he started using, he started getting involved in the heroin, he started hanging out with some less clean users and those people it wouldn't surprise me if he had got hep C now because of that. Because these are the types of people they are, stereotypical junkies you know what I mean, types of people that would rob their own mother ... [It would result in] huge risks potentially, like potentially let's say he gets on a \$100 [of] gear with his mate and this friend has only got one fit. They whack themselves up first, he wouldn't think twice about cleaning it out or even not cleaning it out and whacking himself up and that's stupid you know what I mean, that's fucking disgusting. He'd do that elsewhere but when he came in to our group, we make sure that its safe injecting principles or nothing (Henry, M22).

Henry's belief that Toby engaged in different injecting practices with a network of people who injected heroin invokes notions of the responsible versus irresponsible injector, based on drug of choice. Henry positioned the members of this other network as unclean, implying that they would

participate in injecting practices that had a higher hepatitis C risk. In contrast, Henry positioned his cocaine injecting network as responsible and only approving of safe injecting practices. However, this positioning of the cocaine injecting network below the heroin network in terms of hepatitis C risk does not fit with the research on drug choice, as cocaine use has been shown to be an independent predictor for hepatitis C risk (C. Miller et al., 2002; Patrick, Tyndall, Cornelisse, Li, & et al., 2001; Roy et al., 2007).

Although not identified by Alison, Toby explained that there may be some tension between Alison and Rebecca with respect to Alison's injecting drug use. Toby explained: "No [Rebecca] just wants [Alison] to go to detox and get off it or she's going to break off with her". Although not a specific account of a network relationship breakup, Toby's account regarding Rebecca's desire for Alison to stop injecting could impact on a number of factors for Alison, including her housing and the subsequent need to inject in public, which may increase Alison's chance of contracting another hepatitis C genotype. It may also provide some insights into why Alison may have hidden her drug use from Rebecca, and paints a picture of the tensions that may have to be negotiated regarding maintaining social relationships throughout an injecting career.

6.5 Summary of the South East Sydney network

Overall, the South-East Sydney network members were quite well informed about hepatitis C. All were aware of the risks posed from needles and syringes and other injecting equipment, such as spoons, filters and water. However, all South-East Sydney members also spoke of the time delays that had featured in their personal experiences of accessing this information, and explained that they had become informed about hepatitis C only when accessing services for PWID. For other network members, this lack of awareness may have been the result of hepatitis C not having been identified as a specific virus until a number of years into their injecting career. For the younger members, willingness to access and engage with hepatitis C-related information appeared to be the

major influence on when and where they came into contact with this information. For all South-East Sydney network members, accessing services for PWID had changed their knowledge about hepatitis C transmission and treatment.

All South-East Sydney network members, with the exception of Catherine, believed that hepatitis C was a serious health issue. Perceptions of the seriousness of hepatitis C were generally positioned in relation to HIV, with HIV commonly viewed as more serious than hepatitis C. Kevin was the only South-East Sydney network member who believed that hepatitis C was more serious than HIV due to the larger number of PWID infected with hepatitis C. Toby displayed the most extreme response by describing genuine horror and disgust when discussing hepatitis C. Specific discussions that occurred within the South-East Sydney network related to genotype cross-infection and hepatitis C treatment and although the South-East Sydney network discussed hepatitis C more so than the other networks examined in this research, hepatitis C-related discussions were more likely to occur if they were discussed in terms of generalisations, such as the need to be 'hygienic', 'clean', or 'safe' to avoid hepatitis C transmission. Factors that increased the silence of hepatitis C discussions included the need of PWID to fit in, the stigma associated with hepatitis C and having been challenged in the past about the accuracy of facts offered about hepatitis C. Generalised discussions and disclosure of hepatitis C status did occur, although disclosure was selective and in most cases hepatitis C status was perceived as private information.

Injecting hierarchies were common, although the reason for their existence and their impact on injecting practice and hepatitis C transmission were perceived differently by individual network members. The most divergent views were between Toby and Alison, with Toby reporting that hierarchies were created by perceptions of toughness and age and Alison describing that hierarchies were influenced by a number of contextual factors surrounding drug use. All network members stressed the importance of having access to sterile injecting equipment in any particular injecting

episode. However, the ability to challenge the reuse of equipment could be questioned if finances were shared to purchase the drugs. Further, instances of equipment reuse were identified, especially spoons.

The South-East Sydney network also highlighted a number of interesting factors regarding network breakdown that could affect the transmission of hepatitis C. For Henry, owing money to Kevin resulted in a situation whereby Henry had avoided Kevin and additionally, Henry also claimed that Toby had been excluded from a younger sub-group based on his use of heroin. Toby's exclusion from this sub-group may have resulted in the need for Toby to form new injecting relationships, for example with Alison. Lastly, as a result of Rebecca detoxing and no longer injecting, Alison had to hide her drug use to maintain a somewhat stable place to live. This influenced the place and people that Alison injected with and could ultimately increase her risk of being exposed to another hepatitis C genotype due to public injecting, spoon reuse and an inability to challenge other's practice when resources to purchase drugs were combined.

The next chapter will present the analysis of the data on peer distribution, that is, the distribution of sterile injecting equipment within the networks of PWID. As peer distribution was found to occur in all of the networks, and there has been only limited research on these practices published to date, the analysis of peer distribution is reported as a focused analysis, drawing on data from all networks, and exploring relationships pathways and peer distribution roles.

Chapter 7 Peer distribution

7.1 Overview

Peer distribution is a term used by the advocacy organisation representing PWID in New South Wales – the NSW Users & AIDS Association (NUAA) – to describe the process whereby a person collects sterile injecting equipment from an authorised distribution outlet and then passes this equipment onto others (NUAA, 2009). Peer distribution has also been described in the literature as secondary syringe exchange and satellite needle distribution. However, the use of the term secondary exchange was thought not to be appropriate in a NSW context because of a possible conflation with the activities of ‘secondary’ NSP outlets that provide access to sterile injecting equipment. Therefore, the term peer distribution will be used in this thesis.

Peer distribution is a community-driven but non-sanctioned (by government) practice of collecting and distributing sterile injecting equipment among social networks of people who inject drugs. To identify and discuss the particular practices associated with peer distribution revealed through this study, this chapter will explore four central research questions:

1. Was peer distribution activity occurring in these networks and why?
2. Were specific peer distribution roles and social network relationships pathways evident within these networks?
3. Could peer distribution activity be measured within these networks?
4. Were study participants aware that peer distribution was illegal in NSW?

7.2 Peer distribution activity and rationale

As noted in the methods chapter of this thesis, participation in the peer-distribution sub-analysis was not dependent on network relationships and therefore, data from participants in all four of the networks originally recruited into the study: in total, 34 participants from South-East Sydney, South-West Sydney, Newcastle and the North Coast were included in the peer distribution analysis. The median age of these participants was 31 years, with a range of 16 to 55 years. Fourteen participants (41%) were female and twenty were male (59%). There were comparable numbers in the age cohorts of under 25 year olds (n=11), 26-36 year olds (n=10) and 37+ years (n=13).

All but one of the research participants (n=33) reported engaging in some manner with the distribution of injecting equipment among peers in the months prior to study. Participation in peer distribution was therefore not defined by any demographic characteristic, such as location, age, gender, cultural background or type of drug injected. Four participants currently depended upon peer distribution as their only way of accessing sterile injecting equipment; however, these four participants had also accessed sterile injecting equipment at another point in time from an NSP, pharmacy, outreach or vending machine. All other participants engaged with peer distribution in addition to accessing sterile injecting equipment through those authorised access points.

Participants revealed that there were other members in their social networks, predominantly young PWID, who did not ever access services for PWID, and only ever used peer distribution to access sterile injecting equipment. However, there was no-one who took part in this study who had never accessed services.

The reasons identified for engaging with peer distribution, especially among those who described themselves as being the recipient, were directly related to barriers experienced when trying to

access sterile injecting equipment from authorised services. Micro-level barriers included not having the money to purchase equipment from authorised services, not wanting to keep equipment in large numbers at home (children in the house, living with family and not wanting injecting equipment present for fear of having their drug use exposed), and not having transport to access services, especially in regional areas. Meso-level, or institutional, barriers included equipment only being available from a limited number of service outlets, poor experience with pharmacy staff, equipment being required outside of service operating hours, especially on the weekend, and some services placing limits on the total amount of equipment that could be collected by an individual at any one time. Macro-level factors that influenced the ability to collect equipment from authorised services were more commonly explained in terms of law enforcement. For example, although it is legal to carry sterile needles and syringes on your person in NSW, a number of participants explained that they were frequently stopped by police and carrying injecting equipment could increase the risk of being searched, detained or excluded from the local area. For the younger participants, stigma was also an important macro-level factor that influenced young PWID's willingness to access services.

7.2 Peer distribution roles

Specific roles were identified in participants' accounts of peer distribution. Initially, this analysis progressed by interpreting these roles according to the framework developed by Bryant and Hopwood (2009), which included PWID who pass needles and syringes onto others (distributors), PWID who receive needles and syringes from others (recipients) and PWID who receive and distribute needles and syringes (reciprocal exchangers). However, during the analysis it became evident that there was a need to expand this appraisal of peer distribution activity in order to capture the experiences of both formal and informal categories of peer distribution, depending on the nature, extent and motivations of the individual. Therefore, four categories were developed to describe the main peer distribution roles described in this data: formal distributors, informal distributors, informal recipients and reciprocal exchangers. These categories were developed for this

specific analysis, i.e. they were not terms or labels that PWID in the study used themselves to explain their peer distribution activity. As the role of formal distributor has not been documented previously, the analysis commences with five case studies of the characteristics, scale and motivations of the different individuals who shared their experiences of taking on this role. A thematic analysis of the informal peer distribution roles and social network relationship pathways impacting on peer distribution are presented later in the chapter.

7.2.2.i Formal peer distributor case studies

Formal distributors in this study were characterised as PWID who collected large quantities of sterile needles and syringes (over 100 syringes at any one time) and distributed over 50% of equipment collected at any one time. The role also included the distribution of other injecting equipment, such as spoons, filters, swabs and water ampoules, and the collection and disposal of used injecting equipment. Formal distributors were characterised by the participant's own definition of themselves as a person who provided access to sterile injecting equipment to other PWID as well as a person that other PWID identified as someone from whom they could access sterile injecting equipment. Therefore, the distribution of sterile injecting equipment in the formal distributor role was a defining characteristic; it was not just a casual activity.

There were five participants in the study who were categorised as formal distributors and these formal distributors were located in South-East Sydney, Newcastle and the North Coast. The South-West Sydney network was the only network that did not include an identified formal peer distributor. One participant, Sarath, accessed large amounts of sterile injecting equipment and told me he would distribute sterile injecting equipment to others as required, but none of Sarath's network reported knowing anyone who collected large amounts of sterile injecting equipment. This suggests that Sarath does not typically tell his friends that he has a large supply of sterile injecting equipment, and so he was excluded from the definition of 'formal distributor' developed for this

analysis. Within the formal distributor case studies the main themes that will be explored include the motivations behind peer distribution, the type of people that they distributed equipment to, and an estimate of the size of annual equipment distribution. The estimate calculation used to determine the scale of formal peer distribution activity on an annual basis. The calculation was:

$$x = [\text{No of syringes collected (weekly)} - \text{No of personal injections (weekly)}] \times 52$$

The scale of the distribution of these formal distributors ranged between 21,834 to 34,970 sterile needles and syringes per year (minimum and maximum size distributed), a summary and breakdown of the five formal distributors is contained in Table 2.

Table 1 Formal peer distributor size and outreach

Name	Network	% of total equip distributed	Type of other equipment	Disposal of used equip	Area of distribution	Size Min	Size Max
Jayde *	Newcastle	50%	Swabs Spoons Filters	Yes	Urban	1,508	1,508
Natasha	Newcastle	98%	Swabs Spoons Water	Yes	Urban	6,500	9,672
Chris *	Newcastle	99%	-	Yes	Urban	5,174	5,174
Kevin	South East Sydney	79%	Swabs	Yes	Urban	4,180	9,308
Emma	North Coast	86%	Swabs Spoons Filters	Yes	Regional & rural	4,472	9,308
ESTIMATED ANNUAL PEER DISTRIBUTION SIZE						21,834	34,970

* The minimum and maximum equipment distributed is the same figure for Chris and Jayde because they reported always collecting the same amount of equipment. In contrast, Natasha, Kevin and Emma reported different amounts collected, represented as a range.

7.2.1.1 Jayde (F17) Newcastle

Jayde was a 17 year old Aboriginal-identifying female who lived in Newcastle. Jayde had recently made contact with a youth service that acted as a secondary NSP from which she felt comfortable

accessing sterile injecting equipment. She was the only member of her social network who accessed services to obtain sterile injecting equipment. Jayde collected a box of 100 sterile needles and syringes every two weeks from the service and injected up to three times a day. In total, Jayde distributed more than 50% of the injecting equipment she accessed from the secondary NSP located at a youth service. When Jayde collected needles and syringes from the NSP, she also collected a contaminated waste bin for disposal. Jayde also described distributing swabs, spoons and filters at the same times as she distributed needles and syringes. Using the estimate calculation, Jayde's formal distribution could result in the distribution of approximately 1,508 sterile needles and syringes annually.

Jayde explained that she collected larger quantities of sterile injecting equipment than she personally required:

Yeah I keep half of that [100 box]. I'll keep that in the drawer because I get sick of seeing them use the same needle twice or more. They won't come in [to an NSP] and get it [sterile injecting equipment]. So that's why I pick up extra.

Jayde had assumed the role of formal distributor within her network because her friends would not access services to obtain their own sterile injecting equipment. By providing access to sterile injecting equipment among her friends, Jayde was able to influence the reuse of injecting equipment, which was seen as common within her network of friends. Jayde's participation in peer distribution could also reduce other high risk practices that her friends were participating in, such as breaking into sharps disposal bins in public toilets to access used needles and syringes and group sharing of one needle and syringe. Jayde was aware and mindful of hepatitis C, however, discussing hepatitis C-related issues within her social network was viewed as unacceptable and therefore these discussions did not occur (see Chapter 4, Newcastle network analysis). Therefore, peer distribution seems to have represented an activity that Jayde could engage in that would promote safer injecting practice without the need to explicitly discuss hepatitis C with her friends.

Jayde described her friends' lack of willingness to engage with services and access sterile injecting equipment. Examples of poor experiences with services were explained by Jayde in terms of her own experience when trying to access sterile injecting equipment in the past:

Just in the past I've had some rude, real up 'emselves people that go like 'oh we haven't got any [sterile injecting equipment] left' or 'come back in a fortnight and we'll have some then'.

For Jayde, a poor experience with staff at a pharmacy had a number of effects. The first effect was Jayde was unable to access sterile injecting equipment because the staff member could not supply this equipment to Jayde. Having been refused service directly impacted on Jayde's willingness to access the pharmacy in the future. Given Jayde's negative experiences with accessing sterile injecting equipment in the past, she was more than willing to communicate the positive experience she now had with staff at the youth service to her friends:

I'd be happy to go and pick up some stuff for others but half the time I generally come in and speak with some youth workers, and I'd ring up my mate or my mate would ring me and I say look 'I've talked to them and they're real nice' and already I've had one of them say yes [to going to the service with me].

Jayde had forged a positive relationship with staff at the youth service. Jayde's friends did not access formal or authorised PWID services and therefore the ability to communicate with her friends about the relationship she had with the service could potentially increase the willingness of her friends to attend and utilise the service. Jayde therefore acted a conduit between her friends and the youth service, and represented an important player in providing access to sterile injecting equipment to her friends who would not access services and importantly, in increasing engagement between PWID services and young PWID in that area.

7.2.1.ii Chris (M21) Newcastle

Chris was a 21 year old Anglo-Australian male who lived in Newcastle. Chris participated in a formal distributor role through the provision of sterile injecting equipment to PWID with whom he shared temporary accommodation in a squat. Chris had engaged in this role for a number of years, however, at the time of interview he had moved into stable accommodation and no longer acted as a formal peer distributor. As Chris had limited contact with those that he previously distributed to since moving into stable accommodation, it is unclear whether another person in the squat had taken over the formal peer distributor role. Chris collected 100 needles and syringes each week from a youth service that acted as a secondary NSP, and in total Chris believed that he distributed 99% of all sterile injecting equipment that he accessed from there. Chris explained that at the time he was injecting infrequently, generally once a week or fortnight, and therefore the extent of Chris's formal peer distribution during his time in the squat was estimated at approximately 5,174 sterile needles and syringes across a year.

Chris' motivation to participate in formal peer distribution was explained as wanting to ensure that everyone had access to sterile injecting equipment:

Yeah I was getting a 100 pack [of needles and syringes] ... I used to do it in the squats but that's because I was pretty much like looking out for the [general] health of everyone in the squat. So I used to go into the harm minimisation team grab a 100 pack and go back to the squat and dish them out evenly. I loved it because at least then I knew that everyone had freshies [sterile equipment], everyone had one ... I always had one of the yellow tubs, submarines [for disposal].

Chris self-identified as the person in the temporary accommodation who was responsible for peer distribution, which also included safe disposal of contaminated equipment. Chris' peer distribution was not confined to people he had close relationships with; rather, the distribution of sterile

injecting equipment was available to anyone who frequented the squat at the time. For Chris, altruistic health-based motivations were identified as the main reason for his participation in a formal peer distribution role. However, his participation in peer distribution also seemed to have a positive effect on Chris' self-perceptions. Chris also explained that his participation in formal peer distribution gave him a sense of doing good for others and he 'loved it'. Chris also reported that participating in a formal peer distributor role could have some negative implications:

A negative was either like I'd be off me guts like on the night or enjoying something, I had people coming up all hours of the night, day wanting to do freshies [sterile injecting equipment] and all that and I admit it'd piss me off.

For Chris, being unable to shed the role of formal peer distributor was represented as a potential barrier to maintaining the role. Chris did not share whether he had established any rules or conditions to minimise disruption when he wanted to do other things without interruption.

7.2.1.iii Natasha (F39) Newcastle

Natasha was a 39 year old Anglo-Australian female who lived in Newcastle. Natasha's formal distributor role involved two distinct peer distribution activities. These two activities have been estimated to approximate 6,500 – 9,100 needles and syringes distributed annually. The first activity that Natasha engaged in through her role as a formal peer distributor was providing sterile injecting equipment to a large and diverse population of PWID. For example, she distributed equipment to a friend's house, where large numbers of PWID gathered to inject drugs. This activity involved the distribution of approximately 5,200 needles and syringes annually and where 100% of the equipment she provided was used in peer distribution activity.

The second dimension of Natasha's formal peer distribution practices involved the distribution of sterile injecting equipment to an elderly lady with a disability:

I mean there's one friend I've got that's elderly that's you know, or about middle aged I should say, I think she's about 50 or in her fifties anyway and she's on that's methadone in tablet form. Anyway she shoots them all up and yeah and she's often you know she's got sores all over her and she scratches them and for god's sake. Anyway, I quite often get fits for her and I'll go like get 100 or 200 at a time for her and they last her for a month sort of thing and I'll just do it out of the kindness of my heart, cause I'd rather her use fresh equipment and clean equipment as opposed to not, and so yes basically do it from an altruistic perspective because I'd rather see people doing it, you know trying to do something unsafely I'd rather see people do it as safely as possible so they don't contract Hep C or HIV.

As Natasha explained, she was the sole person responsible for providing access to her friend who was unable to attend services personally. The scale of this activity could result in 1,300 – 2,600 sterile needles and syringes as well as swabs and spoons being delivered to her friend's house annually. Natasha explained that she undertook this activity because of concern for others and to ensure access to sterile injecting to someone who could not access services. For Natasha, peer distribution was motivated by her concern for the welfare of other PWID, which was identified by Natasha as being 'altruistic' and out of the 'kindness of my heart', which were terms that the participant introduced and were not prompted by the researcher. This altruism was also framed as a response to the awareness of injecting practices that could increase hepatitis C or HIV transmission amongst her friends. Despite this, she did not describe having had any discussions about hepatitis C with those people to whom she distributed sterile injecting equipment.

7.2.1.iv Kevin (M47) South-East Sydney

Kevin was a 47 year old Anglo-New Zealander male who lived in South-East Sydney. Kevin explained that he usually collected a box of 100 needles and syringes once or twice a week and other equipment, such as swabs, from the NSP and then distributed this equipment over the course of the

following week from his house. Excluding the equipment he used to inject himself, which was enough equipment to inject three times a day, Kevin could distribute between 4,180 – 9,308 needles and syringes annually, which represented over 79% of all equipment collected from the NSP.

For Kevin, the role of formal peer distributor involved the distribution of sterile needles and syringes and other equipment to PWID when they came to his house:

Generally my mates come around to my place if they want a fit because I'm pretty good at that sort of thing. [I collect a box of] 100 [at a time]. Yeah I get everything. The yellow [disposal] box, you know and all the swabs. Probably a box of 100 will last us, it varies sometimes I've had a box of 100 go in two days you know, but that's people grabbing handfuls sort of thing but probably once a week.

Kevin explained how his friends would come to his place to access sterile needles and syringes as required because his role as a peer distributor was well known. This would usually involve people collecting small amounts of equipment at one time, although at other times it may involve distributing large amounts of equipment. For Kevin, the formal peer distributor role assisted in ensuring that his friends would not be forced to inject with unsterile equipment.

Kevin's motivations to participate in a formal peer distribution role were also based on a perceived need to influence the norms of his social network regarding disposal of used equipment:

People turn up and that because they hold a used fit. They take it with them everywhere you know so that they can use you know. So yeah, I'm always telling people to 'throw it away'. I understand why they carry it around because yeah if they gotta have a shot then. They don't want to get caught with that on them either you know.

Kevin's formal peer distribution role involved a conscious effort to challenge and change people's thinking about and practices regarding the reuse of equipment, which was common if people did not

have replacement injecting equipment. This was achieved through encouraging others to dispose of their used equipment, whilst also providing access to new equipment so disposal could then occur. Kevin believed that this practice could also reduce policing risks, which could occur if people were stopped and searched and found to have used injecting equipment on their person.

7.2.1.v Emma (F43) NSW North Coast

Emma was an Anglo-Australian female who lived on the North Coast. Emma collected between 100 and 200 needles and syringes from a primary or secondary NSP per week and injected up to three times a day. Using the estimate calculation, the size range of Emma's peer distribution activity was between 4,472 – 9,672 sterile needles and syringes annually, depending on whether she collected 100 or 200 needles and syringes per week. In total, Emma distributed over 86% of all equipment she collected. Emma's formal peer distribution role also included the distribution of other injecting equipment such as swabs, filters and spoons. Emma explained that she would like to distribute sterile water ampoules, but could not because her local NSP charged for them which made this practice prohibitive for Emma. Emma also provided equipment disposal services as part of her peer distribution activities. Disposal was usually undertaken through the collection of used needles and syringes in a contaminated waste bin, although Emma also collected used needles and syringes in soft drink bottles if the needles and syringes were capped. Of note was the coverage of Emma's formal peer distribution activities. Emma distributed sterile injecting equipment to PWID to friends in regional towns and villages in Northern NSW, which was a 150 to 200km round trip. The people that Emma distributed sterile injecting equipment to in these areas would not be able to obtain sterile injecting equipment locally, as there were no NSPs, pharmacies or outreach services that serviced these areas.

Emma described a range of motivations for participating in formal peer distribution, although her main motivation was to ensure that her friends injected safely:

The knowledge that my friends are using sterile things is enough. I just, I know how much damage using blunt fits does to your veins, and I don't like suffering through that myself and I just think it's a really good policy to use a sterile one every time.

Emma's own account of her motivations in practicing formal peer distribution was to ensure that she contributed to reducing the harms associated with injecting among her friends, although she made no reference in this part of her interview to being concerned about blood-borne virus transmission. Rather, Emma's motivation was focused on the harm from injecting with blunt needles and the damage that this could do to PWID's veins as a result of the reuse of injection equipment. Like Kevin, Emma also explained that a common practice within her networks was to not dispose of used injecting equipment until replacement injecting equipment was available:

I collect all their stuff and drop off their new fits because often people don't want to hand over oldies unless they got replacement newbies [new equipment]. So that's what got me into taking newbies out to people, that they don't willingly pass up their oldies ... Often people don't have them in proper containers and so when I see that I can put them in containers and shoot them off [to the NSP] because that's a way to get brownie points [with] the universe.

For Emma, the sharing and reuse of equipment amongst her friends was not only influenced by providing access to sterile injecting equipment, it was also strongly influenced by the social norm of not disposing of used equipment. By disposing of used injecting equipment, Emma reduced the amount of time a used syringe was in circulation, which is a practice that could directly influence hepatitis C transmission. What's more, Emma believed that her participation in peer distribution was based on altruistic motivations and a feeling of doing something good for others: getting 'brownie points with the universe'.

Formal peer distribution has not been reported in the literature to date, however, Emma, and all the other formal distributors presented in this chapter, have an important role to play in preventing

hepatitis C transmission in their networks. The extensive, formal and large scale distribution of sterile injecting equipment, disposal of used equipment and ability of to educate their friends about where to access NSP, all need to be acknowledged as remarkable, local practices of harm reduction, so that these effective strategies can be built upon and supported.

7.2.2 Informal peer distribution roles and pathways

The following analysis will explore informal peer distribution roles, including informal peer distributor (distribute sterile injecting equipment to others), informal recipient (receive sterile injecting equipment from others) and reciprocal exchange (receive and distribute sterile injecting equipment). These roles were identified in the study data with respect to four social network relationship pathways, specifically pathways between: (i) close family and friends, (ii) those living in close proximity to each other, (iii) dealers and customers, and (iv) acquaintances.

7.2.2.i Reciprocal exchange between close friends and family

The distribution of sterile injecting equipment to close friends and family was the most common relationship pathway evident in informal peer distribution activity. This pathway was described by most participants, although due to the closeness of relationships, the role of distributor and recipient was not mutually exclusive and therefore reciprocal exchange activity was also common. This was especially common between people in long-term sexual relationships and close friends who were living together. Due to the level of informality in this type of peer distribution, and the shift between recipient and distribution roles, an estimate of the size of reciprocal exchange occurring between close family and friends could not be made.

Reciprocal exchange between those in long-term sexual relationships was described by Mai (F24) and Hao (M28) who lived in South-West Sydney, who had been in a long-term sexual relationship and since the beginning of this relationship both had distributed and received sterile injecting

equipment between each other. As a result both participated in reciprocal exchange roles. Within this relationship the distributor role was more likely to be undertaken by Mai because she appeared to have more access to finances and a car and because she believed she was more responsible. Although not reported by Mai or Hao, it may also be that Mai had assumed the distributor role within the relationship because she was the one who owned the car to get to the pharmacy and because she had the financial means to purchase the equipment once they had arrived at the pharmacy. However, Mai and Hao only accessed sterile injecting equipment from services and between themselves. Neither reported accessing sterile injecting equipment from other friends, family, dealers or acquaintances, although Mai reported that if any of her friends asked for sterile injecting equipment and she had this, she would give this equipment to her friends.

Reciprocal exchange occurring between close family and friends was also identified by Sammy. Sammy was a 45 year old female from the North Coast who explained that she participated in a reciprocal exchange activity, which had been developed informally between herself and her close friends. In this exchange, the role that Sammy would assume was fluid: sometimes she would be the distributor and at other times the recipient. The role assumed at different times was typically the result of logistical circumstance:

Yeah well I've been doing quite a lot of it lately [peer distribution]. The house has become a bit of a gallery ... Well usually I do take it upon myself to do that. It's shared, like it's whoever can get out of the car easiest ... The last lot was bought over to the house by a mate, he just got a 100 [pack of needles and syringes] and he goes like 'if you've run out like here you go'. So yeah, it's just random. Whoever sort of thinks of it at the time I'd say (Sammy, F45, North Coast).

For Sammy, the motivation to participate in a peer distribution role had developed in response to large numbers of people injecting at her house. In most cases, these people would be close friends, including her partner that she lived with. In relation to distributing sterile injecting equipment to

close friends and family, there was a level of fluidity in the role that Sammy assumed because she switched between distributor and recipient roles. This fluidity was explained as an informal understanding between herself and her friends, whereby the recipient or distributor role was determined by logistical or practical circumstances at times. At other times, however, the recipient or distributor role would be 'random'. Additionally, there appeared to be a double layer of peer distribution, where at times a friend would bring large amounts of equipment for Sammy to then distribute to her friends and family.

Claire (F34) and Liam (M46) were close friends who lived in a shared house on the North Coast. Within this relationship, Claire and Liam both distributed and received sterile injecting equipment from each other. This practice had developed between the two as they had recently moved to the North Coast from Sydney. Within this relationship, there was an unspoken understanding that resulted in a reciprocal exchange activity for access to sterile injecting equipment. As Liam explained:

I don't have a large using network up here so the people I do have contact with [it] is generally taken for granted that somebody's got a spare syringe ... Yeah well perhaps you know if I haven't been to the needle exchange or vice versa you know with my friends (Liam, M46, North Coast).

For Liam, reciprocal exchange was explained as an informal activity, whereby if Liam did not have sterile injecting equipment available he would be able to access this from Claire. Liam also believed that the distribution of sterile injecting equipment was an activity that was completely normalised within the culture of drug use in his area. Within the reciprocal exchange role, Liam would swap between distributor and recipient. Claire explained her perception of the reciprocal exchange that she had with Liam in more detail:

Oh I've been going around the corner to that one there but I usually send Liam to get them ... Oh cause I'm lazy ... I mean I do sometimes, but I just haven't lately ...

Oh I don't rely on him necessarily, like I have gone and got them myself but no, it's easier for him to get them sometimes 'cause I sort of work late at night. We just got a system going but I can get 'em myself ... I mean we swap them around [roles for whose turn it is to access equipment] and stuff, it's not set in stone or anything (Claire, F34, North Coast).

Unlike Sammy and Jack, where the role in the reciprocal exchange appeared to be more negotiated, Claire identified an informal system whereby she was more likely to assume the recipient role with Liam acting as the distributor. These roles were not fixed and did change. However, it appears that Claire was more likely to assume the distributor role when she was not working or when Liam was not around.

7.2.2.ii Reciprocal exchange between people living in close proximity to each other

Reciprocal exchange was also common between those people who lived in close proximity to each other. Like those reciprocal exchangers who received and distributed sterile injecting equipment from friends, a level of reciprocity between those living in close proximity to each other resulted in the distributor and recipient role being negotiated over time. For example, Jack generally obtained his sterile injecting equipment from a primary NSP and due to established relationships with neighbours had also become a reciprocal exchanger:

I guess [I get my needles and syringes] here [at the NSP] or me mates 'cause me mates and friends come here too for a box [of needles and syringes] ... [Peer distribution] Yeah, it just saves people sharing. I mean the next door neighbour may not have many fits and he may be hanging out and there may be nothing open and stuff so I guess it's kind of good in a way ... I guess it's daily. I mean if you're using daily then yeah I guess [peer distribution] would be daily yeah, from time to time like it's my turn now sort of thing yeah (Jack, M37, South-East Sydney).

Jack believed that peer distribution was common in his area, explaining that he was located in a social network of friends, who were also neighbours, and within this social network the role of sourcing equipment was reciprocal and rotated: negotiated at the time of accessing equipment or incorporating a more informal rotation. Jack believed that peer distribution had the ability to stop people sharing injecting equipment. Although Jack did not explain what would happen if he did not take his turn to access sterile injecting equipment, it could be assumed that ongoing proximity to his neighbours ensured a level of ongoing reciprocity.

7.2.2.iii Relying upon close friends and family to access equipment

Those participants who received sterile injecting equipment from peers as their only access point assumed an informal recipient role. Within this role, equipment was only accessed from close family and friends. Therefore, the informal recipient in these cases had a mutually exclusive relationship pathway with close friends and family. In this study there were four participants who participated in an informal recipient role only. The role of informal recipient was categorised as people who received small amounts of needles and syringes from others and the reasons for exclusive participation in a recipient role related to concerns about anonymity and developed in response to negative experiences with NSP services in the past. These participants did not access injecting equipment from other authorised services and therefore, the scale of equipment received by informal recipients could be estimated by multiplying the number of injecting episodes per day by a year.

For Scott (M42, North Coast), access to sterile injecting equipment would only occur through distribution from his partner, Kay. Scott explained this reliance in terms of his need to maintain anonymity in the place where he lived:

Yeah [I wouldn't use the vending machine] at the hospital. I wouldn't use [the machine] because like I do a bit of work up there also so generally I don't go and get

'em. I mean I have to be very careful, dodgy about it all, before I was doing this work I was managing [a place] and stuff like that so it's always been like secretive and undercover ... I wouldn't give a shit I'd go wherever or if I was interstate but I live here, work here, so I've got to be careful (Scott, M42, North Coast).

As described here, peer distribution from Scott's partner Kay, was his only point of access to sterile injecting equipment, due to his fear that if others became aware of his injecting practices, his employment would be threatened. As Scott injected three to four times a week, the number of needles and syringes that he received from Kay was approximately 156-208 needles and syringes annually. Interestingly, the need to maintain anonymity was not just a factor for Scott as an individual. His partner also noted the complexity involved in protecting his social contacts (e.g., friends, partners, family) from unwanted attention:

Because my partner works for a [company] and he well, he is a lot more cautious than I am. [It has] put a couple of things into perspective you know ... Just about who you talk to, you know risk factors like with his work. Like I might not necessarily recognise them but they might recognise the car that he drives and they can associate me with that type of place [the NSP] and him you know. So I do have to you know think a lot more (Kay, F34, North Coast).

Kay was very self-consciously aware that her relationship with Scott could also potentially impact on how people perceived Scott, especially if she was seen accessing a PWID service, which she believed would have negative professional consequences for him. Thus, her role in accessing equipment had to be conducted with great caution in order to protect both him and herself.

Tim (M17) and Sue (F17) were in a sexual relationship and lived in Newcastle. Although both Tim and Sue had used pharmacies in the past to obtain sterile injecting equipment, they now only accessed their sterile injecting equipment from a close friend, Brad, with whom they regularly injected. As Tim explained: "Yeah [I get my equipment from my mate] ... Yeah he's cool ... [I get equipment] every

time I go and see him”. For Tim and Sue, reliance on peer distribution was not only a matter of convenience, it had been developed in response to negative experiences that they both had when accessing sterile injecting equipment from pharmacies in the past. Tim and Sue injected three times a week; therefore, the number of needles and syringes that they received from Brad in the recipient role was approximately 312 needles and syringes annually.

Sid (M24, North Coast) also explained that he would receive sterile injecting equipment from Emma, his aunt (identified previously as a formal distributor). Sid explained that he “prefer(ed) to get them [sterile injecting equipment] discreetly sort of thing”. In the past, Sid had accessed sterile injecting equipment from vending machines because he saw this as a discreet service point. However, the \$3 cost of accessing equipment from a vending machine was prohibitive and resulted in Sid not being able to purchase equipment for all injecting episodes. At the time of interview, Sid accessed sterile injecting equipment only from Emma and Sid described this practice as one that he was comfortable with. However, Sid also identified that there may be risks from receiving injecting equipment from others. Sid explained “I guess there’s always the risk of getting contaminated fits”. As Sid injected at least once per day, Emma would distribute approximately 354 sterile needles and syringes to Sid each year.

7.2.2.iii Distribution between dealers and their customers

Two participants spoke of receiving sterile injecting equipment from their dealers. For Henry, receiving sterile injecting equipment from his dealer was common practice:

I think its good policy [that dealers provide sterile equipment]. That way you’re able to get it done, dealed and dealt with. That way the person’s not leaving with the drugs as well so that way the cops can’t be held on to him and also nobody is complaining you know what I mean basically providing a service. Depending on who the dealer is, like there’s a feeling of responsibility as well. Like some of the best

dealers I've seen are people that actually have a responsibility to their customers.

They actually treat it like it's a business and it's not reliable if you're not looking after your customers and the customers aren't coming back (Henry, M22, South-East Sydney).

Henry believed that a dealer who provided access to sterile injecting equipment and a place to inject cared about their customers. However, beyond caring, this was also seen to be influenced by the law enforcement and policing risks of PWID leaving the dealer's house with drugs on their person.

Another risk would be created if the people who purchased drugs then consumed them in close proximity to the place where they were purchased, thereby increasing the risks of the dealer being exposed to police. Henry also explained the supply of sterile injecting equipment as both a social responsibility and an appropriate and effective business decision, assuming that if a dealer was concerned about the health and wellbeing of their clients, this would ensure repeat business.

Kay (F34, North Coast) also spoke about receiving sterile injecting equipment from her dealer; however, Kay's receipt of sterile injecting equipment from her dealer was less formal than that described by Henry. Kay described asking her dealer for sterile injecting equipment when they came to her house, however, this practice was ad-hoc and informal. She explained: "Oh I may ask someone who's delivering if they have any spares but that's about as far as it goes". The major difference between Kay and Henry's practices of relying on a dealer to access sterile injecting equipment was that Henry could assume that his dealer would have equipment when required, whereas for Kay, it seemed more likely to occur if her dealer had spare injecting equipment.

7.2.2.iv Distribution between acquaintances

Unlike in previous studies, the distribution of sterile injecting equipment to acquaintances was also observed in both the informal distributor and reciprocal exchange roles. For example, Ryan was a 22

year old Aboriginal-identified male who lived in South-East Sydney. Ryan was an informal distributor who explained that occasionally an acquaintance would ask him for sterile injecting equipment:

Oh I dunno I usually got 'em. That's why you get a box of 100 [needles and syringes], so I make sure I got some you know when I need it ... I see 'em up the street sometimes and they ask me you know what I mean [if I have equipment]. It doesn't happen that much. They might just be walking along and they say 'hey there' and I give 'em a fit or something and they give me a dollar or two. I mean if they don't have it I give it to 'em anyway (Ryan, M21, South-East Sydney).

For Ryan, distribution of sterile injecting equipment occurred among PWID who were in the same vicinity and not necessary close friends or family. The distribution of sterile injecting equipment to acquaintances or people who are not personally known to the distributor has not been identified in other studies, and this is therefore a notable example. Ryan was also the only participant in this study who suggested that there could be an economic exchange, even a small gain of a dollar or two, involved in peer distribution. As Ryan did not describe the same practice with people other than acquaintances, it is unclear whether the same monetary exchange would occur when he was distributing sterile injecting equipment with friends, family or neighbours. However, as monetary exchange was not reported in any other relationship pathway or peer distribution role type, within this study, economic exchange for the distribution of sterile injecting equipment could not be described as common.

The distribution of sterile injecting equipment to acquaintances also appeared to occur when study members and their friends injected in other people's houses. For example, Sammy, (previously mentioned informal peer distribution between close family and friends), may have also distributed sterile injecting equipment to acquaintances because her house had become a gathering place for people to use drugs. Although in most instances the people who came to Sammy's place were close friends or those living in close proximity to each other, these same friends could also bring others

who were not known to Sammy. Although Sammy did not speak in any depth as to this activity, if people were to bring their friends to Sammy's house and they required injecting equipment, it could be assumed that Sammy distributed sterile injecting equipment to acquaintances. As another example, as people and their friends, who may be acquaintances, also injected at Kevin's place and the squat that Chris had lived in (reported in formal distributor section), their peer distribution activity could be likely to be received by acquaintances. Furthermore, Natasha also distributed large amounts of sterile injecting equipment to a friend's house where people also congregated to use drugs and as a result would have distributed sterile injecting equipment to acquaintances. Although the distribution of sterile injecting equipment has not been reported to occur between acquaintances, these secondary accounts of peer distribution do suggest that this does occur in this type of relationship.

7.2.3 Legal implications of peer distribution

In NSW, the law regarding distribution of sterile injecting equipment falls under *The Drugs Use & Misuse & Trafficking Act 1985*, which states that the provision of sterile injecting equipment is illegal and thus prohibited. In NSW, it is legal to possess needles and syringes under amendment (11 [1]) of the *Act*. This amendment provides exemptions to the *Act*, granted by the NSW Minister for Health, so that the distribution of sterile injecting equipment can occur legally. The current exemption only applies to those organisations that have sought exemption and the nominated people within the organisation to whom the exemption applies. PWID are not exempted under the *Act* and therefore it is illegal for them to distribute sterile injecting equipment to other PWID.

In this study, awareness of the legal implications of participating in peer distribution was low, as only four participants, including Natasha (F39) from Newcastle, Dung (M32) from Newcastle, Ruby (F43) and Joshua (M55) from South-East Sydney, were aware that it was illegal for PWID to distribute sterile injecting equipment among their injecting networks. Therefore, 30 participants (88%) of

participants in this study were unaware that the distribution of sterile injecting equipment within the networks of PWID was illegal. The following section will review participants' understandings of legal and policy contexts surrounding peer distribution and their motivations for participating in an activity that is illegal.

7.2.3.i Confusion about legal and policy issues

The majority of study participants (n=30) were unaware that distributing sterile injecting equipment to friends and acquaintances was illegal. For those who were unaware of the legality of peer distribution, a sense of confusion arose when discussing the legality of peer distribution. As Sammy explained:

I'm pretty sure that it's um OK [to give sterile equipment to your mates]. Oh sorry, it's not OK for me to give one to someone but it is in the needle and syringe program. Well I dunno. Actually it probably is legal but not an open packet. Perhaps, maybe if it's still sealed? No, I'm not actually totally sure (Sammy, F45, North Coast).

In Sammy's response, she initially tried to distinguish whether peer distribution was legal or illegal by discussing various models of sterile injecting equipment peer distribution, such as the difference between herself and the NSP. However, her understanding became more confused when she tried to explain the legality of peer distribution in terms of the product and whether there was a difference between the distribution of open or sealed packets of syringes. This example highlights the confusion that PWID face when trying to understand the policy and legislation that governs the carrying of sterile injecting equipment and this confusion will continue to impact on PWID willingness to access NSP for sterile injecting equipment.

Joshua was also aware that peer distribution was illegal; however, there was a level of confusion generated by different legal and policy contexts of peer distribution and self-administration:

No, well you can't supply something that's not legal. I mean it's not legal to own a syringe. I mean it's as simple as that. It's illegal if you say you're going to use it for illegal activities but I mean but then you're admitting to illegal activities that's self-administration. Once again 'cause whose gonna say to you 'are you gonna use it?' I mean either way they got ya, you know it's a charge. So either way I fuckin' got 'em. Who are you? The fuckin' needle police? (Joshua, M55, South-East Sydney).

Joshua initially linked the illegality of drug use with the syringe that was used in the drug process. From this understanding, Joshua explained the legality in terms of the similarity which he saw between peer distribution and self-administration. In either context, Joshua explained that participating in injecting-related activities could leave people open to charges from law enforcement. However, he also questioned how the law would be monitored by referring, in a flippant way to the 'needle police'. Although there was confusion about the ramifications of policy and legal contexts surrounding peer distribution, awareness of the legal implications appeared to have little influence on people's decision to participate in peer distribution as notions of altruism and low perceived risk of being charged under the law. As a result, all participants spoke of the contradiction that this law had with the aims of harm reduction. These motivational issues will now be explored.

7.2.3.ii Notions of altruism

Overwhelmingly, the decision to engage in this illegal activity was explicitly motivated by altruism, particularly to reduce injecting-related harm (acquisition of HIV and hepatitis C and damage to veins) and to assist their peers to dispose of used equipment safely. These issues were seen to take priority over the legal implications of engaging in peer distribution as a prohibited activity. For example, as Natasha put it:

You know I mean I know it's illegal and everything. Basically I'm willing to take the risk of you know yeah doing that [peer distribution] illegally rather than see

someone be stuck with hep C or HIV for the rest of their life (Natasha, F39, Newcastle).

In the above example, Natasha explained that her participation in peer distribution was based on altruistic intentions and this altruism overrode any legal or criminal consequences that would arise due the distribution of sterile injecting equipment. In fact, Natasha described a conscious willingness to take on the legal risk of distributing sterile injecting equipment to ensure that her peers injected safely and to influence the prevention of blood-borne viruses, including hepatitis C.

7.2.3.iii Low perceived risk of legal implications

Participants also reported that they had not known anyone who had been arrested for peer distribution activities, suggesting that they may have been led to believe they would be unlikely to get into trouble for these practices. For example, Dung was also aware that it was illegal to participate in peer distribution; however, he believed that this was not a law that deserved to be respected:

I am, I do yeah [know the legal implications of peer distribution]...It doesn't mean much because I've never, ever heard of anyone being put in jail for sharing a fit [or] for giving someone a fit. I think someone's health, your health, is much more important ... I don't think that rule should apply ... Yeah, that's such a stupid rule (Dung, M32, South-West Sydney).

In the above example, Dung questioned whether he could be charged with possession of injecting equipment under the law. Like other study participants, Dung also located his participation in peer distribution in an informal health provider role, where his ability to provide sterile injecting equipment to his peers was valued over the law. Further, Dung explained the anomalies of the law for health promotion and harm reduction goals and considered this law to be 'stupid'.

7.2.3.iv Conflict with the goals of harm reduction

It was also common for participants' to strongly report that they believed that the law that made peer distribution illegal was in conflict with the goals of harm reduction. For example, Ruby who was aware that peer distribution was an illegal activity, explained:

[Peer distribution is] not allowed ... it's illegal to give somebody else a syringe or drugs or enable them to use drugs ... Oh well I think [the peer distribution law] it's fucked. You know like that's the whole point of peer education and you know trying to maintain a healthy society and community. You know, like [peer distribution] that's best practice and that's what a lot of people assertively go and try and do (Ruby, F43, South-East Sydney).

Ruby also questioned the appropriateness of the law because it contradicts the aims of harm reduction practice. Ruby believed that peer distribution was an effective and common practice that PWID utilised and one that could positively impact the health of PWID. Ruby also explained that she did not think most PWID were aware of the legal implications of peer distribution:

No not really [I don't think people stop participating in peer distribution if they knew about the law]. Some people would probably be more careful you know. [They would probably think] 'what the fuckin' hell? That's fucked' ... Well they'd still be the same because they're still doing illegal stuff anyway (Ruby, F43, South-East Sydney).

Although legal issues did not affect Ruby's participation in an informal peer distributor role, she also explained that she thought if PWID were aware of the legal implications they would be more careful about their participation in peer distribution. However, Ruby also questioned whether the law would discourage peer distribution because PWID were already participating in an illegal activity, drug use, so the implications of the illegality of peer distribution may be ignored by some.

Adam also explained that he was not aware of the legal implications of peer education:

I don't, I could guess [what the legal implications are for peer distribution] but I don't know no ... Yeah 'cause it seems like it's a law that needs to be changed. Yeah but to me it would seem like a policy that actually helping and not harming minimisation of spread of infection (Adam, M27, North Coast).

For Adam, the illegality of peer distribution was seen to be one that promoted, rather than restricted, the spread of viruses, such as hepatitis C. Therefore this law was perceived by Adam to being contradictory to the aims of harm reduction. Adam also reported that he believed that this law needed to be changed so that the law and harm reduction were complementing each other.

Scott was also not aware that peer distribution was illegal, and it provoked an emotional response from him when I revealed this to him:

That's wrong, that's wrong ... Oh you know you'd just say change it and pull your head in. I mean it's crazy, I mean especially if people know about it. It's probably a good thing people don't know about it (Scott, M42, North Coast).

What is interesting about this quote – apart from what it reveals about how important this practice is to PWID – is Scott's use of the Australian colloquial term 'pulling your head in' to illustrate his critique of the role of law enforcement in contradicting harm reduction priorities. Scott also explained that he thought it was probably a good thing that most PWID were not aware of the law, otherwise they would not be as likely to distribute sterile injecting equipment to those people who needed it.

7.3 Concluding remarks

All but one of the 34 study participants reported participating in peer distribution. In most cases, peer distribution activity occurred between PWID in close relationships such as friends, family, neighbours and customers and dealers. However, there were also instances reported where peer

distribution occurred between people who were described as acquaintances. The practice of peer distribution not only provided access to sterile injecting equipment, in the formal distributor role it also assisted in the removal of used syringes from circulation. Both these practices positively influence safe injecting practice, and therefore should be acknowledged as effective strategies to reduce hepatitis C transmission in the networks of PWID. Peer distribution was described as a daily activity and evidence of peer distribution was ubiquitous across the research. Within this activity, four different roles were identified, including formal distributor, informal distributor, informal recipient and reciprocal exchanger. The most commonly reported role was informal recipient or distribution, whereby access to sterile injecting equipment occurred from a number of sources, including authorised outlets and via peer distribution from friends, family or a dealer.

When peer distribution was undertaken in a formal distributor role, the activity was large scale and formally organised. The five formal distributors in this study had the ability to distribute approximately 35,000 needles and syringes annually. The motivations behind formal peer distribution were predominantly altruistic and to ensure that PWIDs loved ones, friends and acquaintances had access to sterile injecting equipment at times when it was needed. Another common motivation for participation was to challenge and change the social norms around the use of sterile equipment and disposal of used equipment, which was evidenced and strongly articulated by members in the Newcastle, South-East Sydney and North Coast networks.

The roles of informal recipient and informal distributor were less defined and in a number of cases, those who participated in informal peer distribution did so in a reciprocal exchange role. The movement between recipient and distributor roles appeared to be fluid and negotiated over time. In some cases, the role was based on a rotation system and in others on circumstance, such as access to transport. Those participating in a reciprocal exchange role described this as informal; however, peer distribution was still a common, and sometimes daily, activity. There were only four

participants who engaged in the informal recipient role and only received sterile injecting equipment from one person who was a very close friend or a family member. Without the formal or informal distributor in each of these four cases, it would be unlikely that these study participants would be able to access sterile injecting equipment when required. However, the reliance on one person to access sterile injecting equipment may at times, also be a barrier to sterile injecting equipment access.

Peer distribution could also be seen to overcome the social risks associated with initiating hepatitis C conversations that were evident within the networks of PWID. However, this same participation also included a legal risk as peer distribution was illegal in NSW (at the time of the study at least), which was a risk only understood by four of the 33 participants who were engaged with peer distribution in some way. Within the networks, there was a considerable degree of confusion about peer distribution, self-administration, and whether the distribution of sealed and opened needle and syringe packs constituted a difference in the criminal implications of these practices. Regardless of actual awareness, all participants believed that the illegality of peer distribution conflicted with the goals of harm reduction and ultimately had the ability to impact on the spread of viruses, such as hepatitis C. All participants wanted to see law reform to decriminalise peer distribution of sterile injecting equipment.

Chapter 8 Discussion

The risk environment framework was initially developed by Tim Rhodes to counter the overwhelming focus on the individual in research on the harms associated with injecting drug use and to re-direct research, service provision and policy attention towards a broader range of factors that are known to influence drug use and health. The body of work emerging from this approach has, in particular, highlighted a number of diverse environmental influences in injecting drug use and related harm, such as those reviewed in Chapter 2. However, there has been little attention paid to date to the micro-social environment, and the social network factors that influence hepatitis C risk and prevention. This thesis has focused on the social network factors that shaped and influenced hepatitis C-related understandings, communication and network dynamics among specific social networks of Australians who inject drugs. This study has therefore added to understandings of hepatitis C risk and prevention via a specific focus on the relevant aspects of social network knowledge, communication and dynamics. By focusing on social networks, specifically how hepatitis C was understood and communicated within each network and how this knowledge and communication influenced the sharing and reuse of injecting equipment, this study has generated new understandings regarding the prevention of hepatitis C. This final chapter will provide a synthesised overview of the three networks analysed in the main results chapters, before reviewing the main findings of the research, including those relating to peer distribution. These findings will be discussed in relation to the research questions and the literature, whilst also considering how these findings might inform and strengthen the development of effective hepatitis C harm reduction responses in Australia, and comparable settings, and may also have some applicability across other areas of blood-borne virus research, such as hepatitis B and HIV. This chapter concludes by identifying the strengths and limitations of the qualitative social network analysis methodology developed for this study, along with concluding remarks.

The networks described in detail in this thesis were purposively recruited from diverse geographic locations in New South Wales, Australia. The first network was located in a regional city in NSW, in an area with high numbers of economically marginalised young people, the second in outer suburban Sydney, in an area with high numbers of South-East Asian migrant Australians, and the third in inner-city Sydney, an area with a demographically diverse population. In comparing these networks, there were specific differences apparent in network membership in relation to socio-demographics, as well as varied drug use characteristics, drug markets, service access and self-reported hepatitis C status: all of which could be seen to influence risk of hepatitis C transmission.

The three networks also differed with respect to network membership and structure, particularly the socio-demographics of the different network members. For example, the network located in South-East Sydney was comprised of people who were typically older than members of the other networks reported in this study and were from Anglo-Australian backgrounds. In contrast, the Newcastle and South-West Sydney network membership was typically younger than South-East Sydney and also included Aboriginal and Vietnamese cultural groups within their membership. Different education levels were also evident, with those in South-East Sydney more likely to have completed secondary school (or Year 12 equivalent), and those in the Newcastle and South-West Sydney network had ceased formal schooling early, typically before completing Year 10. The differences in education levels across the networks could be seen to have influenced not only differences in literacy and other key life skills, but also the ability of network members to access and understand harm reduction information provided by services.

Although the networks reported in this study had similar membership numbers, the structure of the networks was also diverse, with evidence of a number of different sub-groups within each of the networks reported. Interestingly, there were no identified injecting relationships outside of the South-West Sydney and Newcastle networks, whereas most of the South-East Sydney network spoke

of other important relationships, including a number of people with whom they had injected with recently but were not disclosed during the research process. At least one member in each network reported close relationships with family, such as Jayde in Newcastle and Rebecca in South-East Sydney. However, the South-West Sydney network was distinctive in that all participants identified close and current relationships with family members as important to their relational networks. As these relationships were not discussed in detail in this study, the influence of family in social networks has not been emphasised. The membership of all networks reported in this study had also undergone change over time and this changing membership could be seen to directly influence the acquisition, preparation and consumption of drugs in those different settings. What is also interesting to recognise are the differences between networks with respect to hepatitis C infection status. All members of the South-East Sydney network self-reported as hepatitis C positive, all members of the Newcastle network self-reported as hepatitis C negative and two of the six members of the network located in South-West Sydney self-reported as being hepatitis C positive. This difference in self-reported hepatitis C status between the networks is interesting in highlighting the different composition of membership in networks of people who inject drugs, and how self-reported status appeared to have little impact on hepatitis C-related knowledge or how hepatitis C was subsequently discussed in the networks recruited to this study.

Drug use characteristics also varied between the networks. For example, all South-East Sydney network members had been injecting for over seven years and poly drug use was common, whereas all members of the Newcastle network were somewhat new to injecting and typically only injected their drug of choice, which was heroin in one sub-group and speed in the other sub-group. In the network located in South-West Sydney, heroin was predominantly used and poly drug use was only reported by one network member. All South-West Sydney network members who participated in the study also reported receiving methadone maintenance at the time of interview, which was not reported in any other network. Cultural factors also appeared to influence the way that drugs were

used: as all members of this network spoke about smoking heroin for at least five years before transitioning to injecting, a practice not reported in the other networks. Another difference evident between and within the networks with respect to drug use was the ability of different network members to procure and subsequently prepare drugs. As these factors directly influenced the transmission and prevention of hepatitis C within the networks, issues related to acquisition and preparation are discussed in more detail later in this chapter.

Across all network study sites, barriers to service provision were identified, but this was particularly clear in the accounts of South-West Sydney and Newcastle network members, who described avoiding services because participants did not want to be seen accessing services or identified with injecting drug use and instances where services had not distributed the injecting equipment requested. These service-level barriers were further compounded for members of the South-West Sydney network, as this geographic area had a level of service provision that could only be described as inadequate. Even in South-East Sydney, an area described as enjoying high-level service provision (Bryant, Paquette, et al., 2012), barriers to service were identified. However, the barriers reported in South-East Sydney were typically related to the pragmatics of collecting injecting equipment, such as the opening hours of services or the types or cost of equipment distributed. Given the significant barriers to accessing injecting equipment in all networks, it is notable that so many study participants responded to these barriers by engaging in the distribution of sterile injecting equipment within their social networks (which will be discussed in detail in the later part of this chapter).

As this study will also comment on young people who inject drugs, it is important to highlight at the beginning of this discussion that age, as a socio-demographic variable that defines who young people are, was a diverse and slippery concept. For example, Henry was 22 and lived in the inner-city of Sydney and Chris was 21 and lived in Newcastle. Both presented as equally street-savvy, both

started injecting at a very early age and had spent a significant amount of time living in squats through their early to late teens. However, Henry was hepatitis C positive, engaged with services, had a reasonable level of knowledge of hepatitis C, and was considering treatment options, while Chris was hepatitis C negative, only recently engaged with NSP services, and although he had been tested for hepatitis C, had never had a discussion with a health professional about hepatitis C. Age was also a slippery concept with respect to the reporting of young people's experiences and exclusion from NSP services in this study. In NSW, NSP service delivery is governed not only by the Needle and Syringe Policy (NSW Department of Health, 2013a) but also by the Children and Young Persons (Care and Protection) Act 1985, which states that "depending on the age of the child, a clinical decision may be required to determine that it is appropriate to provide injecting equipment" (NSW Department of Health, 2013a, p. 14). The Act defines a child as a person under the age of sixteen years and a young person are over the age of sixteen but under the age of 18 years. Under Section 27 of the Act, it is mandatory to report any child (aged under 16 years) who may attempt to access NSP to the NSW Department of Community Services (DoCS) as a person at risk, however, the reporting requirements for young people aged sixteen to eighteen years is not guided by directive, rather it appears to be at the discretion of the service. The negative experiences of accessing sterile injecting equipment described by the younger participants, such as Jayde in Newcastle and Rebecca in South-East Sydney, highlight a need to further inform and train NSP workers, particularly with respect to access rights and the importance of engaging young people so that they will return to access NSP services in the future.

Although these kind of differences were evident between the networks with respect to members' socio-demographics, drug use characteristics and service engagement, this discussion will now focus on describing the overarching insights developed through the detailed analyses of these diverse networks, with particular reference to the generating new knowledge on the hepatitis C-related

understandings, communication and network dynamics in these social networks of Australians who inject drugs.

8.1 Making sense of hepatitis C understandings within diverse networks of people who inject drugs

Knowledge and understanding of hepatitis C is crucial in prevention because poor knowledge is associated with an increased risk of transmission (Balfour et al., 2009). In this study, significant delays were reported by individual network members regarding their first contact with hepatitis C-related information. There were also quite varied understandings of hepatitis C evident between networks, as were the often distinct differences in hepatitis C-related knowledge between members of the *same* social network. As knowledge gaps and confusion related to hepatitis C were more evident in the accounts of the younger network members in this study, the section will also make specific comment on the implications of these findings for younger people who inject drugs.

Across each of the three social networks described in this study, evidence was provided of significant delays, often as long as three years but sometimes as long as eight years, between first experiences of injecting drug use and becoming aware of even the most basic hepatitis C-related information. This confirms the findings of an Australian study on initiation to injecting drug use, which also observed a long time before relevant information was accessed (Bryant, Ellard, et al., 2012). However, a particular dimension of the delay that has been observed in this thesis was that for most network members, there was almost no awareness of hepatitis C at all when injection was initiated. This lack of awareness was influenced by a number of different factors. For example, Henry in South-East Sydney explained that due to his young age he was more interested in having fun than learning about hepatitis C. However, Henry's poor literacy may have also have influenced his ability to access and absorb information. In contrast, inadequate service provision in the South-West Sydney local area was clearly responsible for the lack of engagement of network members with relevant

information. A lack of awareness of what hepatitis C is and what it means for health makes it impossible for those who are at risk of acquiring hepatitis C to identify those risks and to subsequently modify their injecting practices to avoid them. This lack of awareness will continue to see young people, or those new to injecting, at an increased risk of hepatitis C.

A lack of knowledge regarding hepatitis C was also compounded by a lack of awareness of services for PWID, which was particularly limited in the early years of injecting among younger participants of all networks, a finding also reported in previous Australian studies (Abelson et al., 2006; Bryant, Ellard, et al., 2012; Treloar & Abelson, 2005). When young people in this study became aware of where to access sterile injecting equipment, reluctance to access services was influenced by instances of young PWID being refused access, particularly in pharmacy settings. For example, Jayde and Sue in Newcastle both spoke of being refused access, whilst Rebecca in South-East Sydney reported the risk of being seen by family members entering NSP services as a barrier. These barriers may be related to the young age of these study participants, or to something more particular about the specific geographic setting they were in. In either case, this suggests that training in harm reduction and Needle and Syringe Program policy, particularly in pharmacy settings, is needed and this training should pay particular attention to highlighting the direct link between being refused access to sterile injecting equipment and increased risk of acquiring hepatitis C.

The experiences that young PWID have with services early in their injecting career can have enduring effects, particularly given the small proportion of people under 25 years who actually make use of NSPs in NSW (Iversen & Maher, 2013). In this study, the needs of young PWID, particularly those under sixteen years of age, require further thought particularly in relation to the provision of NSP. Participants across all networks reported initiating to injecting at a young age, and for some this was as early as 13 years. Unsurprisingly, all young network members in this study spoke of social, economic and service marginalisation, which influenced, and subsequently reduced, young people's

willingness or ability to access services for sterile injecting equipment. As most people regard “substance use by 13-15 year olds as evidence of a problem” (MacLean, Bruun, & Mallett, 2013, p. 207), the construction of young people’s drug use as problematic or pathological, particularly for those people under the age of sixteen years, will continue to negatively influence young people’s willingness to access and engage with services ‘without identifying themselves as deficient’ (Treloar & Holt, 2006).

Another factor that may influence the willingness of young people to access NSP is the current design of youth-based services, which typically provide services to young people aged 12-25 years. Ultimately, more knowledge is required to further understand young people and their drug use, however, research ethics, policy exclusions and DoCS mandatory reporting systems may preclude or exclude access to NSP to those PWID under the age of sixteen. In addition, as youth-based services provide services to a wide-range of young people, aged 12-25, and by attempting to reach a wide range of ages, youth-based services “may inadvertently obscure the particular service needs of early teenagers” (MacLean et al., 2013, p. 206). Further consideration should also be given to increasing NSP delivered through youth-services, including appropriate training for staff about issues facing young PWID, as well as reviewing policy and legislation that excludes, or creates barriers, for young people to access sterile injecting equipment when required.

When hepatitis C transmission risks were identified by participants, these were more commonly articulated with reference to individual instances of sharing and/or reusing injecting equipment. This is not to suggest that participants were simply reproducing accepted understandings of hepatitis C, rather they were drawing upon those understandings in constructing their own set of ideas about hepatitis C transmission risk and prevention, which were not always accurate. For example, blood-to-blood contact was identified as a hepatitis C transmission risk by all study participants. However, saliva, which is not an accepted hepatitis C transmission risk, was also identified by at least one

member in each of the three networks. This belief seemed to be linked to confusion between the different types of viral hepatitis (A, B, & C) and which has also been reported among other populations of PWID (Rhodes et al., 2004) and in the general community, such as younger people in an Australian university environment setting (Hopwood et al., 2012). Given the hepatitis C knowledge gaps and confusion over the different types of viral hepatitis among a number of different populations, consideration should be given to the implementation of a mass, community education campaign on viral hepatitis.

Although study participants were aware of the hepatitis C transmission risk posed by the reuse of needles and syringes, this awareness was only recently realised for some of the younger members of the Newcastle network, who described previous injecting episodes where it was common to share one needle and syringe amongst a group of friends. Confusion and lack of awareness of the hepatitis C transmission risk associated with other injecting equipment (beyond needles and syringes) was also evident in the networks, a finding that has also been reported in the research literature (Carey et al., 2005; Heimer et al., 2002; Thorpe et al., 2002). The hepatitis C transmission risk of other injecting equipment, particularly the spoon used to prepare drugs, was not well understood. This lack of awareness was again most prominent in the accounts of the younger study participants, even those who were accessing NSP services. In this study, the spoon was a specific focus of analysis on transmission risk, as all study participants mentioned using this item in drug preparation. However, participants rarely mentioned other injecting equipment, such as the tourniquet, filter, water and the general injecting environment. The absence of discussion about the perceived transmission risk of other injecting equipment, besides spoons, is a limitation of this study. Although there is work done in other settings exploring the knowledge and perception of risk of other injecting equipment (Pouget et al., 2012), this research has not been replicated in an Australian setting and therefore should be considered in future research.

Although there was confusion or knowledge gaps surrounding hepatitis C transmission among study participants, study participants still spoke of actively modifying behaviour to reduce their risk of transmission. The cleaning or bleaching of used injecting equipment was reported across all networks, however, the efficacy of cleaning strategies used by study participants would not reduce hepatitis C transmission risk, a finding reported in other Australian studies (Carruthers, 2005; Nathani et al., 2010). For example, within the South-West Sydney network, bleaching was a commonly employed risk reduction strategy when sterile injecting equipment could not be accessed. However, only Tai was correctly informed about the process for bleaching used needles and syringes. As Tai did not socialise or discuss injecting related issues with other network members, this information was not disseminated to other network members. Within the South-East Sydney network, Kevin was the only network member who described the correct bleaching process. As with Tai, Kevin also reported that he did not talk about bleaching with other network members, but his focus was instead on distributing sterile injecting equipment (see Chapter 7). As ongoing misconceptions and confusion surrounding transmission, especially those practices used by PWID to reduce the transmission risk when sharing injecting equipment, indicates an ongoing need to educate and re-educate populations of PWID about the hepatitis C transmission risk when sharing or reusing injecting equipment, even when this equipment may have been cleaned.

Among other network members, there also appeared to be more attention paid to the transmission risk of the needle and syringe, whereas the transmission risk of other injecting equipment, particularly the spoon used to prepare drugs, was either not known or not prioritised. This lack of prioritisation was seen to occur even where network members were well aware of the hepatitis C transmission risk posed from the sharing and reuse of other injecting equipment, a finding also reported in the research literature (Thorpe et al., 2002). Importantly, the considerable variability in knowledge, and subsequent prioritisations of hepatitis C risk of needles and syringes and other injecting equipment, both between and within the different networks settings in this study, will

require harm reduction and prevention strategies that acknowledge, and expect, variability of knowledge between populations of PWID, which will require harm reduction programs to be designed and implemented to meet the specific needs of those different populations of PWID (Maher, Li, Jalaludin, Chant, & Kaldor, 2007).

Awareness of the long-term health effects of hepatitis C was also low across all networks. For example, participants did not typically seem to understand that hepatitis C could have long-term health implications, such as liver disease, liver failure and hepatocellular carcinoma, but most importantly most did not believe that hepatitis C could lead to death. This lack of understanding was common in this study, a finding also reported in the literature (Doab et al., 2005; Treloar et al., 2012). Additionally, this underestimation occurred in this study even among those network members who knew they were hepatitis C positive or who viewed hepatitis C as extremely serious, and it is may be that this belief has been influenced by the asymptomatic progression of the hepatitis C virus (A. Freeman et al., 2001). However, as the population burden and health outcomes of chronic hepatitis C increase (Maasoumy & Wedemeyer, 2012), hepatitis C-related deaths are likely to also increase (Grebely & Dore, 2011b). There is a need to therefore ensure that information related to the long-term health effects of hepatitis C is made available to networks of PWID, particularly focusing on the implications of not pursuing hepatitis C treatment. However, the dissemination of this information will need to be carefully managed so as to not further stigmatise those living with hepatitis C or creating unnecessary or further fear of hepatitis C, which may create further barriers in engaging PWID with services that aim to prevent and treat hepatitis C.

Within the three networks analysed in detail in this research, there were also variable understandings of hepatitis C treatment, despite all study participants having been tested for hepatitis C, except Jayde in the Newcastle network. All participants were aware that there was a treatment available for hepatitis C, although understandings of what a treatment regime involved

and its curative effects differed between and within networks. Interestingly, those people with hepatitis C, with the exception of Catherine and Kevin in South-East Sydney, even those who had undergone or were considering hepatitis C treatment, did not speak about their genotypes. The absence of genotypes in those networks members' accounts of hepatitis C is important because genotypes directly impact on hepatitis C treatment. In addition, a lack of knowledge about genotypes could also negatively influence the transmission of hepatitis C within the study's networks. For example, Rebecca and Alison in South-East Sydney self-reported as hepatitis C positive, had injected together and were aware that hepatitis C had different genotypes. However, as they had not requested this information when tested, they would therefore not be aware of their genotype. These low levels of hepatitis C knowledge in a high testing environment also point to inadequate pre- and post-test counselling, which confirms the findings of a number of Australian and international studies (Aitken, Kerger, & Crofts, 2002; O'Brien et al., 2008; Treloar, Newland, Harris, Deacon, & Maher, 2010).

Hepatitis C testing provides an important opportunity for the dissemination of hepatitis C-related information to PWID, however, this opportunity has not yet been realised in Australia. This missed opportunity is vital to address and suggests that attention be directed to ensuring health professionals, particularly general practitioners, are informed about the most effective ways to treat and care for hepatitis C so that every opportunity to raise awareness of treatment options among this population is maximised. While others suggest that hepatitis C testing should be seen as not only a bio-medical practice, hepatitis C testing should be seen as a 'psycho-social intervention to prevent risk behaviours' so that every opportunity to educate PWID about hepatitis C transmission can be utilised (Loxley, Bolleter, & Carruthers, 2001). In addition, the hepatitis C educational and health service needs of health professionals has not been researched in Australia for almost a decade (Gupta, Shah, & Ward, 2006) and therefore a better understanding of the different awareness and training needs of the diverse range of health professionals groups who treat, test and

care for people with hepatitis C will be required to adequately address any limitations of current pre- and post-test counselling processes.

It has been claimed that current hepatitis C policy and practice has failed young people (and those new to injecting), as potentially life changing information is not reaching this group in a timely manner (Hagan, Thiede, & Des Jarlais, 2004; Maher et al., 2006; C. Miller et al., 2002). The significant delays observed in this study, and others, regarding when hepatitis C-related information was first accessed will continue to mean that young people, or anyone new to injecting, are at an increased risk of acquiring hepatitis C (Hahn et al., 2002; Merkinaite, Grund, & Frimpong, 2010). As it is not possible to predict which young people may begin injecting, so that hepatitis C-related education can be targeted to these young people, the strategic delivery of hepatitis C-related information to young people requires further thought. The current approach to delivering hepatitis C education through PWID-based services may not be effective in reaching young people or those new to injecting and therefore, targeting young PWID as a specific sub-group for hepatitis C prevention requires further thought. In this study, the way that young PWID understood and subsequently responded to hepatitis C was variable not only between networks but also *within* them. Developing effective hepatitis C-related policy and practice for young people at risk needs to ensure that this information reaches the target group. Current responses have typically resulted in significant time delays in knowledge, including awareness of even the most basic hepatitis C-related information. To ensure that appropriate and socially relevant knowledge is reaching people at risk, especially young people, the current practice of delivering hepatitis C-related information primarily through NSPs has not been effective in reaching or engaging young people and this suggests that, at a minimum, other youth-friendly NSP distribution modalities may be required.

Differences in understanding regarding the transmission risk of hepatitis C were evident across all networks, not only among the younger network members; however, this difference should not be

surprising given the extensive body of literature that acknowledges risk as a socially construction (Douglas, 2013; Mayock, 2005). Where the focus is on individual and rational perceptions and responses to risk, and this construction will allow for a clearer (but admittedly more complex) understanding of how populations of PWID think about and negotiate risk (Duff, 2003). A socially constructed understanding of risk also highlights that there is not a one-size-fits-all model suitable for informing all PWID about hepatitis C. For example, a study assessing prevention education to young PWID suggests that messages about risk, such as ‘don’t share or new fit for every hit’, are not sufficient because they do not acknowledge the social nature of injecting (Carruthers, 2003). Rather, any hepatitis C prevention and education effort needs to focused both on building awareness and understanding of hepatitis C, whilst also being contextualised and tailored to the specific micro-social settings in which the education effort is intending to have impact (Carruthers, 2007; Mayock, 2002, 2005; Rhodes, 1993, 2009; Winter, Fraser, Booker, & Treloar, 2011).

The identification of different prioritisations and perceptions of risk and subsequent educational needs in this study was evident between networks but also *within* them and this makes any prevention effort more complex. Expansion of peer-based education initiatives in different social and geographical contexts is also required, as these responses are identified as the most appropriate in meeting the hepatitis C-related education needs of PWID and responding to different localised needs (Anderson et al., 2013; Newland & Treloar, 2013). However, the barriers to discussing hepatitis C evidenced in this study may need to be further investigated so that peer education programs, and peer educators, can effectively and appropriately approach hepatitis C within their peer networks. A logical extension of current PWID-based peer education programs would also be to include peer distribution of sterile injecting equipment alongside the delivery of information.

As studies have consistently found the knowledge of PWID regarding hepatitis C to be poor, confused and containing many omissions (Bryant, Ellard, et al., 2012; Cox et al., 2008; O’Brien et al.,

2008; Treloar et al., 2011), the findings from this study highlighting the knowledge, or lack thereof, of individual network members was alarming but not surprising. What was striking, however, and potentially new in terms of the research literature, was the fact that even if one or more members of an injecting network was relatively well informed about hepatitis C, this did not translate as shared knowledge across all members of the same social networks and sub-groups: even within couples in long-term sexual relationships. Given the significant difference in hepatitis C-related knowledge and accounts between members of the same social network, it raised the question: why were people not discussing hepatitis C within their networks and what influence did this communicative silence have on the understandings of, and responses to, hepatitis C in these networks?

8.2 Negotiating the general silence surrounding hepatitis C within injecting networks

The findings from this study highlight that within a number of diverse social, sexual and injecting relationships, it was uncommon to discuss hepatitis C and even less common to disclose a positive hepatitis C infection. Most participants in fact recalled very little hepatitis C-related discussion occurring within their networks and described what could more appropriately be understood as a pervasive or general silence in relation to hepatitis C. The data reported in this study suggests that hepatitis C was for the most part a silent phenomenon. Hepatitis C was typically cast as a serious issue and discussion about the virus were avoided. As a result, participants deliberately concealed views, opinions and knowledge about hepatitis C, as well as any information they held regarding their own status. Hepatitis C discussions were actually so uncommon among these networks that when these discussions were initiated by others, the younger network members in this study recalled responding to, or being met with surprise, shock, embarrassment and in one extreme case, violence. These negative responses were reported even in instances where hepatitis C-related discussions were extremely short or contained little information.

The silence surrounding hepatitis C in this study also seemed to be, at least in part, influenced by the seriousness and stigma ascribed to this infection: all but one study participant viewed hepatitis C as a serious issue or condition. This silence appeared to be reinforced by legitimate fears that initiating hepatitis C-related discussions could result in embarrassment, shame, rejection and isolation. As a result, some of those network members with hepatitis C would not initiate even the most general conversations related to hepatitis C due to a fear that this may potentially draw attention to their hepatitis C status. For example, Tai in South-West Sydney and Toby in South-East Sydney both spoke about how they consciously avoided all conversations that might draw attention to their hepatitis C status, whilst Kevin in South-East Sydney reported being deliberately selective in relation to disclosure. The pervasive silence surrounding hepatitis was also perpetuated by a belief that those who did not feel at risk of contracting hepatitis C had no need to engage with information or conversations about it. This lack of engagement was particularly relevant in the Newcastle network, where Tim and Sue in Newcastle and Binh in South-West Sydney reported not needing to discuss hepatitis C because they did not believe they knew anyone who had contracted the virus. In addition, younger participants also reported that they had been challenged by other network members when introducing the topic of hepatitis C facts into conversation, which could influence the future willingness of these individuals to initiate future discussions about hepatitis C.

The silence surrounding hepatitis C also seemed to be influenced by the fact that participants were clearly more interested and motivated to engage in pleasurable conversations on other topics, rather than opening up conversations about hepatitis C, which could be associated with negative, painful or uncomfortable emotions (Irwin & Fry, 2007). Discussions about where to access drugs and the effect of law enforcement were more likely to be recalled by participants than any other type of conversation, a finding which has also been reported in other Australian studies (Bryant, Ellard, et al., 2012; Treloar & Abelson, 2005). Discussions about having fun, going out and taking drugs were

most common amongst the younger network members, as were conversations about movies, computer games and family. As well as recognising that hepatitis C can represent an unacceptable topic for discussion and that there can be many other more pleasurable conversations in which to participate, it must be acknowledged that participants may not recall all the detail related to discussions in the context of a research interview.

The strength and nature of the network relationships also appeared to influence the level of discussion and the silence surrounding hepatitis C and may have had a greater impact on those people with weaker relational ties within networks. When network relationships were described as acquaintances, even general conversations about hepatitis C with other network members were rare, and thus opportunities for sharing information were fewer. In these circumstances, people would come together to pool money, consume drugs and each then go their own way. Described by Toby in South-East Sydney as “same shit, different score”, when people who were less socially connected came together there was more interest in simply completing the injecting episode and going their separate ways, than in building social relationships or having conversations with others, particularly about sensitive issues such as hepatitis C.

Although silence was prominent, discussions were more likely to occur in these networks if the topic of hepatitis C was approached, and subsequently, discussed in generalised terms. These generalisations were commonly articulated through the use of ‘hygiene narratives’, a finding concurrent with that previously reported in the literature (Rhodes et al., 2008; Rhodes & Treloar, 2008). These hygiene narratives were most prominent in the South-East Sydney network where Rebecca described the “need to be clean and careful” to avoid hepatitis C transmission, while Henry believed there was no need to discuss hepatitis C with another user if they looked like a “clean user”. Hygiene narratives were also apparent in the way that people in sexual relationships negotiated hepatitis C transmission risk: for example, Catherine described how she and Kevin

engaged in injecting practices that were viewed as “clean” to avoid genotype cross contamination. However, constructing something as 'clean' also perpetuates the notion that others are ‘unclean’ and examples of this from the data include Toby and Kevin describing other PWID as “dirty” and “putrid”. Interestingly, as all South-East Sydney network members used such generalisations to discuss hepatitis C, this may be influenced by these network members who all reported living with hepatitis C for a number of years, therefore having more experience and time to work around the silence surrounding hepatitis C within their networks.

Discussing hepatitis C in terms of hygiene narratives served to protect the speaker from any possible negative responses from others. However, these same generalisations contributed to maintaining the more general silence surrounding hepatitis C. In fact these generalisations could be seen to be a ‘code’ used by PWID who have had time to negotiate the silence surrounding hepatitis C within their networks. However, this code may not always be obvious and therefore not understood by young PWID. Importantly, these hygiene narratives also provided a symbolic function, identifying some PWID as clean and responsible and others as not clean and therefore irresponsible (Fraser & Treloar, 2006; Rhodes & Treloar, 2008). The practice of labelling particular network members as clean or unclean became particularly important for network members when trying to negotiate the silence surrounding hepatitis C status and subsequent responses to hepatitis C transmission risk occurring within these networks (discussed in the next few sections). Ultimately, the silence surrounding hepatitis C within these networks was nuanced both between and among the study networks, however, overwhelmingly this silence created an environment whereby most people did not feel that they could discuss hepatitis C freely. These barriers severely constrained the sharing of hepatitis C-related information and the ability to check the accuracy of knowledge held by individual members in a network setting. However, this did not mean that hepatitis C prevention was not occurring within these networks; rather these results suggest that hepatitis C prevention services, particularly peer education, require a clearer understanding of the different barriers to discussing

hepatitis C in different network settings. Given the barriers to initiating and discussing hepatitis C evidenced in these networks, the silence surrounding the disclosure of a hepatitis C infection in these networks was even more pervasive than the silence surrounding more general conversations about hepatitis C. The barriers to disclosing a hepatitis C infection in these network settings will now be discussed.

8.3 Appreciating the challenges of disclosing a positive hepatitis C status within injecting networks

Fears of disclosing a positive hepatitis C status are common, however these disclosure dynamics are typically reported in health-care settings and the hepatitis C disclosure dynamics occurring within networks of PWID has been relatively unexplored in the research literature (Ahern et al., 2007; Anti-Discrimination Board of NSW, 2001; Fraser & Treloar, 2006; Paterson et al., 2007; Treloar et al., 2013). In this study, fears of disclosing a positive hepatitis C status within immediate friendship and injecting networks and trusted others were clearly evident. Negative reactions were commonly reported as a result of disclosing positive hepatitis C status, particularly in the accounts of the younger study participants. Responses to disclosure reported by participants included avoidance, physical violence and exclusion from social and injecting networks. Most importantly, negative responses to disclosure within these networks were *expected* by most study participants and this expectation served to perpetuate what Rhodes et al have termed “a culture of silence regarding hepatitis C antibody status disclosure” (Rhodes et al., 2008, p. 1443). Given the seriousness attached to hepatitis C by these networks, and the silence surrounding hepatitis C discussions more generally, reluctance to disclose hepatitis C status can be viewed as based on legitimate fears. Similar findings have been documented in the literature, such as fears of rejection and social exclusion (Fraser & Treloar, 2006; Owen, 2013; Wozniak et al., 2007) as well as more complex forms of internalised guilt and shame (Fraser & Treloar, 2006; Sutton & Treloar, 2007).

Although it was more common to not disclose a positive hepatitis C status within the networks investigated in this study, there were instances where disclosure did occur. However, this disclosure was more likely to be reported by those in sexual relationships and most commonly involved a brief discussion at the beginning of the relationship, where both partners were tested for hepatitis C, followed by an enduring silence about the issue thereafter. There were four couples in long-term sexual relationships who took part in this study and only one couple, Kevin and Catherine in South-East Sydney, reported discussing and negotiating hepatitis C over the course of their relationship. This negotiation was based on a fear of cross infection, as they had different hepatitis C genotypes and did not want to be infected with another type. The agreement reached between Kevin and Catherine included ongoing service engagement, hepatitis C testing and discussion between the two about test results. For the other three couples in this study, discussion of hepatitis C occurred only once, at the beginning of the relationship, when both were tested for hepatitis C. As all couples in this study recalled discussions about hepatitis C with their partner occurring directly after hepatitis C testing, promoting the need for ongoing hepatitis C testing in sexual relationships could be an appropriate way to create space to discuss hepatitis C in these specific relationship settings.

Disclosure outside sexual relationships was very uncommon and where this occurred, it was strategic and selective. The constraints on hepatitis C disclosure within these networks were so significant that those who identified themselves as influential within their networks also reported significant barriers to discussing living with hepatitis C openly. For example, Kevin in South-East Sydney explained that he believed he was respected and influential within his network, however, he “didn’t tell everyone I got hepatitis C. There’s a stigma attached to it”. In addition, for some network members living with hepatitis C, there appeared to be a persistent fear of initiating hepatitis C conversations more generally, as stated earlier, since these types of conversations could potentially draw attention to people’s own hepatitis C infection. As well as individual instances of disclosure being extremely selective, most participants “wouldn’t ask” other network members about their

hepatitis C status because this was considered “private information”. The barriers to hepatitis C disclosure operating in these networks are also likely to have discouraged study participants from discussing, or seeking new information, about the hepatitis C risks that may need to be negotiated in any injecting environment.

Although – or perhaps because – it was not common to disclose hepatitis C status, and because there was a general avoidance with regard to hepatitis C discussions, network members in this study reported inferring a hepatitis C infection status of other network members. For example, a negative hepatitis C infection status was inferred on other network members because they believed their friends would disclose among themselves if they were hepatitis C positive. This was most prominent in the younger network member’s accounts, where it was also common to not want to engage with hepatitis C because they didn’t know anyone who had disclosed a hepatitis C infection. Network members also inferred a negative hepatitis C infection status on others if they were perceived to be “clean users”. Conversely, inferring a positive hepatitis C status on others was most commonly related to negative impressions of a person’s injecting practice, specifically those people viewed as “dirty” and “putrid” and with whom network members would not inject or in some cases would completely avoid.

There is a small, but increasing, body of evidence reporting on the practice of disclosing a hepatitis C infection as a harm reduction strategy within PWID populations (Burt, Thiede, & Hagan, 2009; A. Kim & Page, 2013; Owen, 2008; Smith, et al., 2013). However, these studies have been very much focused on understanding the individual as the unit of analysis and therefore the influence of social network dynamics on disclosure in these particular micro-social settings has not been explored. This literature, which is from the USA and is therefore more focused on HIV as a risk for PWID, identifies a strong relationship (and tension) between disclosure of HIV status, stigma and social support, whereby people living with HIV may not disclose a HIV positive status to others if they believe that

they would be stigmatised as a result. In these instances, stigma was a social cost that directly influenced disclosure (Serovich, 2001), especially where this disclosure would risk their own or others' exclusion or rejection from their networks (Shelley, Bernard, Killworth, Johnsen, & McCarty, 1995; Smith, Rossetto, & Peterson, 2008).

Importantly, although it should not be expected that all people will disclose their hepatitis C status at all times, the almost complete lack of disclosure occurring within the networks recruited into this research could be seen to directly influence hepatitis C transmission risk as this risk was, in most cases, difficult to appraise and subsequently negotiate. Furthermore, an inability to disclose a positive hepatitis C status within social networks of PWID is likely to contribute significantly to worsening hepatitis C-related stigma and the burden of living with hepatitis C, as close personal relationships have been identified as primary sources of support for pursuing treatment and other forms of hepatitis C care (Hopwood et al., 2010). Given the influence that hepatitis C-related stigma had on the networks reported in this study, the following discussion will focus in more depth on how hepatitis C-related stigma contributed to the reproduction of particular forms of social inequality within networks of PWID, an area of scholarship that has received little attention.

8.4 Reproducing stigma and inequality within social networks of people who inject drugs

A number of research studies have drawn attention to the significant influence of hepatitis C-related stigma and discrimination in producing negative health outcomes and perpetuating social inequalities for people living with hepatitis C (Butt, 2008; Butt, Paterson, & McGuinness, 2008; Hopwood et al., 2010; Hopwood & Southgate, 2003; Hopwood et al., 2006), although this research has tended to focus on medical and treatment encounters. Within these contexts people with hepatitis C have been reported to be more likely to have had poor experiences, to be blamed for coming into contact with the virus and to be subjected to inappropriate, discriminatory or

exclusionary practices (Day et al., 2004; Hopwood & Treloar, 2003). Most importantly, this body of evidence has highlighted that hepatitis C has the potential to create a 'spoiled identity', which can in turn justify the removal of social supports and other forms of social exclusion (Fraser & Treloar, 2006). As it is thought that hepatitis C-related stigma generally originates from outside drug injecting networks (Rhodes & Treloar, 2008), the ways in which hepatitis C-related stigma is enacted and experienced within networks of PWID has received little attention in the research literature and therefore, the social practices and interactions underlying these processes are not well understood (Owen, 2013).

In this study, quite specific forms of hepatitis C-related stigma were evident in accounts of social relations between network members. Network members were clearly aware that hepatitis C was cast as a "an attribute that is significantly discrediting" (Goffman, 1963, p. 13) and it appeared this had become internalised for study participants, whereby most uncritically accepted and reproduced these discrediting social representations of hepatitis C. For example, Kevin in South-East Sydney expressed strong emotions about hygiene, including the use of the term 'putrid', a clearly moralising statement. While network members may not be themselves responsible for generating the stigma associated with hepatitis C, their acceptance of these discrediting representations legitimised historically entrenched forms of social inequality and structural vulnerability (Rhodes, Harris, & Martin, 2013), which serve to devalue, or exclude, those people who were, or were believed to be, hepatitis C positive.

The silence surrounding hepatitis C which was evident in these networks was likely to be exacerbated by hepatitis C-related stigma, primarily through fear and shaming (Tangney & Dearing, 2002). Hepatitis C-related stigma and subsequent fear and shame were most prominent in accounts of those people with, or believed to have, hepatitis C who had been avoided or socially excluded by members of their social networks. This included exclusion from the injecting environment and in a

more extreme account, complete exclusion from any social contact. For example, Mai in South-West Sydney spoke of avoiding people she believed to be hepatitis C positive, whilst Jayde in Newcastle reported avoiding a friend who had disclosed he was living with hepatitis C. Fear of exclusion exacerbates shame, which was explained by some in this study who knew they were hepatitis C positive but seemed to be unwilling to draw attention to this within their networks. For example, Tai in South-West Sydney explained how he would not disclose his positive hepatitis C status within the network because this disclosure would make him feel uncomfortable, awkward and scared. Whilst in a more extreme account, Toby in South-East Sydney who was hepatitis C positive described genuine horror and disgust at the thought of discussing hepatitis C with anyone.

Issues of fear and shame have not been addressed in any detail in the hepatitis C literature, however, these study findings confirm those reported in a study that explored the influence of shame in alcohol and other drug counselling settings (Gray, 2009, 2010), as well as in a study of hepatitis C-related stigma in men who have sex with men, whereby shame not only led to real or perceived expectations of social and sexual rejection, it also in turn fostered increased feelings of fear and shame (Owen, 2008, 2013). Most importantly, hepatitis C-related stigma in the networks investigated in this research could be seen to significantly contribute to social suffering and the reproduction of inequality and exclusion of people with hepatitis C (Bourgois, Lettiere, & Quesada, 1997). The normalisation of hepatitis C, or indeed the presence and expectation of transmission, did not necessarily result in a reduction in hepatitis C-related stigma. Rather, one of the ways in which hepatitis C-related stigma was enacted within the social networks of PWID involved in this study was through stereotyping based on hygiene narratives (as previously described). These stereotypes led to the formation of contrasting representations of PWID, between those who were believed to be 'responsible and clean' or 'irresponsible and unclean' (Fraser, 2004). The allocation of these representations to particular network members, and their acceptance and recognition within the

networks, reproduced forms of inequality within the networks because they provided justification for the removal of social bonds as well as the right to participate in shared injecting episodes.

These findings have important implications for social and health research that draws on theories of stigma, that is the physiological and psychological harm deriving from political and economic inequality that mean some populations face greater vulnerability (Farmer, 2009). Within the networks explored in this study a number of adverse outcomes resulting from hepatitis C-related stigma were evident and included “believing oneself to be inferior, withdrawing as a consequence, believing another to be inferior [and] rejecting them as a consequence” (Sayce, 1998, p. 332). Importantly, hepatitis C-related stigma operated in a number of different environments, compounding the effect of hepatitis C-related stigma occurring within the networks of PWID. The compounding effects of multiple layers of stigma were evocatively described by Tai in South-West Sydney, where he described hepatitis C and injecting-related judgement, labelling and exclusion, occurring sometimes simultaneously, in a number of different contexts, including his social network, as well as from family, community and service providers.

These socially embedded forms of inequality can only be changed by altering the policy and social structures that encourage hepatitis C-related stigma in the first place and therefore, structural interventions targeting all macro-levels of the risk environment, such as the macro-social, macro-economic, macro-physical and macro-policy levels, will be required (Cook, Purdie-Vaughns, Meyer, & Busch, 2014). In addition to macro-level (structural) interventions, interventions targeting stigma will also be required at other levels of the risk environment. For example, health professional groups and services have an important role to play in educating people and developing interventions that aim to minimise hepatitis C-related stigma. These types of interventions may be best placed within peer-based organisations, which generate alternate discourses about hepatitis C. For example, evaluations of hepatitis C-related peer education programs have been found to increase the

discussion of hepatitis C among networks of PWID (Newland & Treloar, 2013), whilst other research has highlighted that prevention efforts can be utilised that do not explicitly mention hepatitis (Friedman, Sandoval, Mateu-Gelabert, Meylakhs, & Des Jarlais, 2011; Harris, Treloar, & Maher, 2012; Mateu-Gelabert, Sandoval, Meylakhs, Wendel, & Friedman, 2010; Mateu-Gelabert et al., 2007). Importantly, these findings highlight the need for peer education programs to be developed and implemented in particular networks in particular geographical settings, where the content and delivery of messages will need to be cognizant of the different understandings of hepatitis C and the barriers to discussing or responding to hepatitis C in those different network settings.

8.5 Responding to the micro-social dynamics of hepatitis C risk in social networks

When the focus is moved from the individual to social relationships as the unit of analysis it becomes possible to appreciate and acknowledge the influence of the diverse array of people, events and practices that surround drug use in specific micro-social contexts. Relationships are complex social phenomena, they do not just exist and nor are they static. Therefore relationships need to be both formed and maintained and these relationships can influence the choices people make about their drug use. Within this focus, Bourgois' concept of a 'moral economy' (introduced in Chapter 2) was useful in understanding how specific micro-social dynamics were negotiated in these networks settings. Within a moral economy perspective, maintenance of social network relationships is believed to be strongly influenced by the rights and obligations of friendship, including the web of mutual obligations occurring within those relationships (Bourgois & Schonberg, 2009). These moral economies often result in particular social rules, roles and hierarchies being formed and maintained, which in this study were seen to have a direct influence on a number of factors that influence hepatitis C transmission and prevention leading up to, and including, the injecting episode.

One of the ways that moral economies were understood by network members in this study was through the identification of network rules, especially those rules governing injecting practice. In this study the public health imperative to not share needles and syringes was articulated as a rule, or requirement of participation, across all networks. The expectation to always have a sterile needle and syringe available for every injecting episode was communicated as a social norm, influencing what was considered acceptable within the networks (Latkin, Forman, et al., 2003). Having a used needle and syringe in the injecting episode was therefore viewed as an unacceptable practice across all networks, and this rule was often expressed in moral terms. As Sue in Newcastle put it, “even if I’m on a binge I know wrong from right”. Those that would share or reuse needles and syringes were therefore often cast as not caring and lacking an understanding of socially acceptable practices within the network, or injecting culture more broadly. Exclusion from the injecting environment was also reportedly employed as a response to those who brought used injecting equipment into an injecting episode. In an extreme example, Toby in South-East Sydney suggested that he “would kick a person’s teeth in” if a person did not have sterile needles and syringe for an injecting episode in which he was present.

Although the sharing and reuse of people’s needles and syringes was articulated as an unacceptable practice and something only ‘others’ did, there appeared to be significant dissonance between agreement with social norms and rules regarding acceptable injecting practice and the sometimes unescapable everyday practicalities that may necessitate the reuse of needles and syringes on occasion. These unescapable practicalities were typically explained in terms of the need to reuse one’s own needle and syringe on occasion. For example, Chris in Newcastle and Toby in South-East Sydney, who both spoke of reusing their own needle and syringe due to barriers to accessing services when needed, stated that they would never reuse or share others’ equipment. Although Chris and Toby may believe that this reuse did not constitute the same risk as sharing or reusing

another person's needle and syringe, they have not taken into account the injecting equipment that the used needle and syringe has come into contact with prior to reuse.

In other instances, what was defined as sharing and reuse was not always clear, particularly when the reuse of injecting equipment occurred between those network members who were in intimate relationships. For example, Mai and Hao in South-West Sydney routinely reused their own needles and syringes and although Mai also identified the use of marking individual syringes to minimise the risk of her unintentional reuse of Hao's equipment, the reuse of needles and syringes within this sexual relationship was not perceived to be as serious as the sharing of injecting equipment outside of their relationship. If unintentional sharing of needles and syringes occurred between them, this was not perceived as a hepatitis C risk because both Mai and Hao believed they were hepatitis C negative. Conversely, Catherine and Kevin in South-East Sydney reported a conscious decision to not share needles and syringes, which was explained in terms of them having different hepatitis C genotypes. Although the literature reporting on the sharing and reuse of injecting equipment in couples is scant, those that have reported on this issue suggest that relational factors such as intimacy, love and trust, rather than the infection status of the person's partner, are most important in a couple's decisions to share (or not) share needles and syringes (Bryant et al., 2010; De et al., 2007; Rhodes & Cusick, 2000; Rhodes & Quirk, 1998). However, within this study it appears that for all couples, the hepatitis C status of their partner could be seen to directly influence injecting practice, including the priorities they placed on sharing and reuse of injecting equipment.

The requirement to always have sterile water, spoons, tourniquets and filters was not nearly as universally articulated as a rule across the networks compared with the strongly articulated rule for the use of sterile needles and syringes. Although in a number of cases, the reuse of other injecting equipment in the drug preparation process could be seen to be influenced by a lack of knowledge regarding this transmission risk (as described in section 8.2 of this chapter), the reuse and sharing of

other injecting equipment was not believed to be as serious a risk as sharing and reusing needles and syringes. For example, a number of participants in the South-East Sydney and Newcastle networks routinely carried a spoon on their person and would commonly use this spoon in any injecting episode. The reuse of spoons in injecting episodes occurred even where participants were aware of the hepatitis C transmission risk that the spoon posed and there was no talk about “kicking a person’s teeth in” when discussing the reuse of spoon in the injecting episode, as had been the case for needles and syringes. The lack of knowledge and prioritisation of the transmission risk was even more evident for other injecting-related equipment, such as water, filters and tourniquets, as these pieces of equipment were rarely mentioned by this study’s network members during the research process, a finding also reported in the literature (Hagan, Pouget, & Des Jarlais, 2011).

In addition to rules, particular social network dynamics, specifically the need to pool resources, were identified as an important factor in the micro-social environment that influenced how people accessed, prepared and used drugs in network settings. The pooling of resources has been previously identified as a micro-social driver of hepatitis C transmission (Hahn et al., 2002) and in this study the pooling of resources was not just financial: rather, it involved the pooling of a number of relationships, resources and skills required to enable, and then enact, the injecting episode. Most prominent in these accounts was the importance of arranging access to a dealer, transport to and from a dealer, money for the dealer, equipment for the injecting episode, a place to inject, and skills in preparing and injecting drugs. The nature and stability of particular social network relationships and the individuals’ ability to contribute, or not, to the diverse factors identified above can be seen to have created forms of social inequality in the injecting episode, resulting in injecting hierarchies particular to specific episodes. For example, Tim and Sue in Newcastle pooled finances with Brad, and Brad would then procure the drugs and subsequently prepare and inject Sue and Tim. Given that Brad was in control of most of the factors leading up to and including the injecting episode, the ability of Sue and Tim to challenge practice may be compromised.

As has been noted in the literature, injecting hierarchies determine the place of the individual in the injecting episode, thereby directly influencing the risk of coming into contact with contaminated injecting equipment (Bourgois et al., 2004; Davis & Rhodes, 2004). For example, Mai in South-West Sydney, had access to a home, a car, money, and the dealer, and was therefore responsible for arranging all of the necessary components for an injecting episode, including a safe place to inject. These factors placed her first in use of equipment and drugs in any injecting episode with her partner Hao, which is a gendered power dynamic not typically reported in the research literature as males are more commonly reported to exert power in the relationships of PWID (Bryant et al., 2010; Evans et al., 2003; Sherman, Latkin, & Gielen, 2001). Conversely, Sue from the Newcastle network, did not acknowledge the complex interplay of structural inequality and vulnerability in her position in her network. Sue was reliant on her boyfriend Tim to inject and their friend Brad to access and prepare drugs and supply injecting equipment. Further, Sue reported that she had no interest in watching drugs being prepared, which could influence her ability to identify risk and subsequently challenge practice, leading up to and during the injecting episode. The influence of gender and risk was not a focus of this research, although the gendered dynamic described by Mao and Hao in terms of Mao being in control is very interesting. As there was only one case example of this gendered dynamic in this study, caution was placed on interpreting this case with respect gendered power among populations of PWID. To be able to comment on this dynamic with more confidence, future research should consider couples where women appear to have more agency within their sexual relationship.

These findings highlight the complex social network factors that could influence injecting hierarchies and subsequent forms of inequality within the injecting episode, and as such contribute directly to hepatitis C transmission risk. In the literature, it is common to examine injecting hierarchies in terms of gender, with female PWID commonly portrayed as having less power to negotiate their place in injecting hierarchies (Bourgois et al., 2004; Maher & Hudson, 2007; Shannon et al., 2008). Gender

inequalities in this body of literature are typically viewed in terms of “a straightforward demographic dynamic following the patriarchal logics of gender relations (older men dominating younger women)” (Bourgois et al., 2004, p. 256). However, issues of inequality and gender appeared to be more nuanced in this study, whereby injecting hierarchies (and inequality) appeared to be influenced more by the ability to contribute, or not, to the resources and process leading up to and including injecting. This is not to say that gender is not an important factor in hepatitis C transmission risk, rather inequality within the networks of PWID is complex and traditional gender roles may not always capture the complexity of understanding of hepatitis C risk in these micro-social environments.

When participants spoke of consciously being able to exert a level of influence and control during drug preparation or injecting practice occurring in group settings, the place in which the injecting episode took place was significant. For example, Kevin in South-East Sydney explained that injecting with others in his home made it possible to distribute sterile injecting equipment that he had stockpiled, whilst also providing a safe place for his friends to inject. Whilst for Jayde in Newcastle, the ability to control aspects of the injecting environment was more fluid and ultimately dependent on whether she injected at her own home, where Jayde “was in the drivers’ seat”, or when she injected at her sister’s house, where her sister was “the big show”. Importantly, the place in which an injecting episode took place was consciously acknowledged as directly affecting injecting practice and agency in these settings. Furthermore, given that a number of the network members (across all networks) in this study had unstable housing or had been homeless, housing as a significant macro-physical environment will continue to adversely impact on hepatitis C transmission risk within these networks.

Conflict, instability and social network turnover (as reported in Chapter 2) has been implicated in syringe sharing and HIV transmission (Cepeda et al., 2011; Tyler, 2008). However, issues of network

conflict and instability, together with social networks generally, have received little attention in the hepatitis C literature. In this study, social relationships were not always viewed as stable and conflict or network breakdown could be seen to influence hepatitis C transmission risk. In some instances, conflict was explained in terms of monetary concerns, whereby network members described avoiding those to whom they owed money. The impact of conflict on injecting practice and risk was reported by Chris in South-East Sydney who had avoided Kevin because of a debt and which in turn removed Chris' access to housing, social supports and a safe place to inject. Where networks broke down, different and sometimes new social and injecting relationships needed to be formed and these new relationships could involve a lack of awareness of the hepatitis C status of networks members as well as creating inequalities in access to drugs and injecting equipment. For example, Toby had been excluded from Henry's sub-group and therefore formed new relationships with people where he did not discuss hepatitis C and was therefore unaware of their hepatitis C status. All of which could be seen to impact on an individual's ability to exert control within the injecting episode.

These study findings regarding the influence of social network dynamics highlight that where people do not contribute to drug sourcing, preparation or injecting, others typically take control of these processes, and thereby have a more direct influence on hepatitis C transmission risk and prevention (such as Kevin's distribution of sterile equipment in his house). Additionally, when people have little interest in the processes surrounding drug acquisition, preparation and use, they may not identify or negotiate hepatitis C risk at all. A lack of interest was reported by Sue in Newcastle, who explained that she did not pay attention to the person preparing drugs because she had seen it before and was not interested. Most importantly, although social network factors related to sourcing drugs, equipment and injecting were identified by network members as important micro-social influences surrounding drug use, for the most, these network-based issues were not consciously acknowledged or articulated as factors that could influence hepatitis C transmission. The lack of acknowledgement

regarding the influence of social network relationships among PWID networks is important because the social network influences that increase or decrease the risk of hepatitis C transmission may not be easily identifiable or modifiable. Acknowledgement of the social network factors that could influence hepatitis C transmission in this study needs to also better appreciate that hepatitis C harm reduction has focused, almost exclusively, on the individual. This focus on the individual has been described as a disconnect between public health messages that aim to prevent hepatitis C transmission and the lived experience of PWID (Bourgois, 1998; Bourgois et al., 2004; Dwyer et al., 2011; Fraser, 2013) because current hepatitis C prevention efforts fail to recognise or respond to the range of social, economic and structural factors that can influence the lives of PWID, of which injecting practice is likely to only be one part.

8.6 Legitimising peer-led responses to hepatitis C risk reduction

As a result of the pervasive silence and stigma attached to hepatitis C, members of the social networks described in this study developed strategies to avoid explicit hepatitis C-related discussions while also identifying practical ways to reduce the risk of transmission. The most prominent response to injecting-related harm, including hepatitis C, evident in this study was that of peer distribution. Peer distribution involved distributing or receiving sterile injecting equipment within social networks of PWID. In fact, peer distribution was so widespread and accepted that all but one of this study's participants were able to easily describe recent examples of peer distribution activity. The distribution of sterile injecting equipment occurred across a number of different social network relations, but particularly through close relationships ties typically reported in the literature, such as friends, neighbours, family and dealers and their customers (Murphy et al., 2004). Although not as common as other relationship pathways, peer distribution was also found to occur between acquaintances in this study, which has not previously been documented in the research literature. Within the networks recruited into this study, peer distribution appeared to take on two distinctive roles, including formalised large-scale distribution and informal, small-scale distribution. The

definition used for formal peer distributor in this study was when an individual went to an NSP and collected significantly large amounts of sterile injecting equipment (i.e. over 100 needles and syringes a week) with the conscious intention of distributing the majority of this equipment through their networks. People who distributed large amounts of sterile injecting equipment also reported deliberately assisting in the disposal of used equipment. The motivations behind this large-scale distribution were clear: to ensure access to sterile injecting equipment and disposal of used injecting equipment to reduce possible incidents of reuse, and to therefore contribute to reducing the harms associated with the injection of illicit drugs.

Formalised, large-scale distribution networks of sterile injecting equipment were evident in all the networks investigated in this research, except the network located in South-West Sydney. This area suffered inadequate service provision and other significant environmental factors that negatively influenced the ability of these network members in this site to stockpile injecting equipment for later use. Five individuals who took part in this study reported that they undertook formalised, large-scale peer distribution. These five people were estimated to distribute and dispose of almost 35,000 needles and syringes annually. Most importantly, this peer distribution activity reached people who did not access services and would not otherwise have had access to sterile injecting equipment, including women, young people, people with disabilities and people in regional areas where there was no easy access to services. As well as providing large-scale, accessible syringe supplies for their network members, those providing large-scale peer distribution may not have explicitly discussed hepatitis C with their friends, however, those participating in peer distribution were reported to refer a friend to service, told other PWID where to find an NSP or discussed injecting related harm, a finding also reported in another Australian peer distribution study (Fisher et al., 2013). These equipment distribution and service referral pathways are crucial, especially in environments where people do not want to openly talk about hepatitis C. As has previously been suggested throughout this discussion, the silence surrounding hepatitis C in the networks of PWID requires peer education

requires further thought, especially around relevant information provision that positively influences hepatitis C prevention without having to explicitly mention, or focus on, hepatitis C.

Informal peer distribution was embedded in the networks of PWID as all but one participant had used informal peer distribution to receive or distribute sterile injecting equipment. Within these networks, there was a clearly articulated expectation that if a person required injecting equipment and another person had this, the equipment would be given to them. Informal, individual instances of peer distribution activity appeared more fluid and based on circumstance and therefore an estimate of the size of this informal peer distribution could not be made. Within the informal peer distributor role, it was common to shift from acting as distributor to recipient and for these roles to be negotiated and shared. For example, a person would collect injecting equipment on one occasion and then expect another person to do this on the next occasion. This practice was most commonly reported to occur between those people in sexual relationships as well as people living in close proximity to each other.

These study findings regarding peer distribution within acquaintance relationships and the identification of formal, large-scale peer distribution networks are novel, but peer distribution as an alternate route for sterile injecting equipment access has been extensively documented for over a decade (Burrows, 2006; Huo et al., 2005; Latkin, Hua, Davey, & Sherman, 2003; Lenton et al., 2006; Lorvick et al., 2006; Murphy et al., 2004; Snead et al., 2003). So, why has peer distribution as an alternative distribution route not received more attention in a policy environment that calls for at least a doubling in syringe supply over the next few years (Kwon et al., 2009)? When looking at Australia's response to increasing syringe supply, there appears to be more interest in scaling up existing distribution routes, such as increasing NPS sites and operating hours (Australian Government Department of Health and Ageing, 2010a), and less interest in acknowledging the complex social factors that shape risk and enabling environments (Moore & Fraser, 2006).

Peer distribution was a conscious, collective and mobilised action among the networks of PWID to ensure that their friends had access to sterile injecting equipment when required. Importantly, the practice of peer distribution positively challenges peer and group norms' surrounding the sharing of injecting equipment because it is occurring within the community to which it is going to have impact (Carruthers, 2007; Friedman, 1999; Friedman & Aral, 2001; Friedman et al., 2007; Grund et al., 1996; Neaigus et al., 1994; Neaigus et al., 1996). Many significant voices have called for peer distribution to be acknowledged as a legitimate harm reduction response, recognising that the current law that makes peer distribution illegal is "nonsensical and anomalous" (NSW Users & AIDS Association, 2009, p. 12), and in conflict with the goals and harm reduction and hepatitis C prevention. Given the evidence regarding peer distribution practice, as well as the more practical reasons to advocate for peer distribution, such as the need to find more effective ways of reaching young PWID (Bryant, Ellard, et al., 2012), a number of peak bodies have been strongly recommending that further action be directed towards making relevant legislative change so as to ensure that peer distribution can be more easily encouraged and validated (Legal and Discrimination Working Party of MACBBVS, 2014). Furthermore, when the social dimensions of PWID are ignored, issues identified by PWID as influential to their lives and their drug use become at best "second-order issues next to empirical, clinical and political considerations" (Fry, Treloar, & Maher, 2005, p. 450). When PWID issues become second order issues, opportunities for change are missed and this ultimately serves to maintain the position of PWID as passive recipients or illegitimate actors, rather than active partners in Australian harm reduction responses. This research provides further evidence to support these claims, as well as encouragement regarding the possibilities that lie in existing social relationships of PWID for scaling up the distribution of sterile injecting equipment.

8.7 Methodological reflections

The innovative use of a qualitative social network approach in this study has allowed for a close examination of the social network factors that influence the ability of individuals, and sometimes whole networks, to understand, discuss and respond to hepatitis C in their networks. However, it is also important to note limitations of this research, including the context in which the research was conducted, as well as limitations of the qualitative approach and the social network research design employed in this study. With respect to contextual limitations, although there is clearly much work remaining to be done to effectively prevent hepatitis C in populations most at risk, harm reduction in Australia is more than a high profile discourse; it is in many ways an established policy framework. This means that NSPs and related services are made available in ways that are simply inconceivable in many other settings, for example, in the United States where needle and syringe programs are largely illegal (Beletsky, Grau, White, Bowman, & Heimer, 2011). These contextual issues influenced the way that the research on this topic was conducted, in terms of recruitment, participant accounts and data analysis.

The qualitative approach employed in this study introduced some methodological limitations, which need to be acknowledged when interpreting these findings. The principle limitation of the qualitative approach was the relatively small sample sizes of the networks identified and investigated in this research. No attempt was made to achieve representativeness of entire networks or broader PWID populations and therefore the findings presented in this thesis are not claimed to be generalizable or transferable to other situations, networks or populations. The qualitative approach, using individual face-to-face interviews, also required participants to recall personal experiences. Recall is believed to be limited, especially where those experiences had occurred a long time in the past (Hassan, 2006) and furthermore may be exacerbated when injecting practice becomes ritualised and habitual practice and therefore, recalling specific behaviours may

not always be possible (Treloar, 2005; Treloar et al., 2008). To overcome recall error, the research focused on recent social network experiences, except where a historical event was important to the data context or interviewee experience. Social desirability was another issue that may have influenced data collection, and subsequent analysis, due to an interviewee's reluctance to report negative experiences, especially where these experiences are perceived as socially undesirable (Patton, 2002).

Another limitation of this study, that also needs to be acknowledged when interpreting these findings, is that the description of a few of the network members is thinner than is typically ideal in qualitative analysis. This can mostly be explained by some participants being very reluctant to engage in sufficient depth in their interviews, which is a recognised challenge in working with marginalised communities (Newman, Bonar et al. 2007). In contrast, other participants were far more willing to provide long and full answers to prompts, providing rich data that was able to feature more fully in the thesis. There also were of course some instances in which answers to questions could have been followed up on more proficiently, and the experience of training in qualitative social research during this study has improved my interviewing skills in this regard. However, it is also important to note that participants also expressed very clearly in non-verbal body language when they were not willing to answer follow up questions on topics of particular sensitivity or challenge for them, which has been noted in the methodology.

The social network design used in this study also introduced a number of limitations, specifically related to the complexity of how the networks were defined, recruited and subsequently analysed in this study. The networks reported in this study were defined as those people identified by the original and subsequent participants with whom they had stable and current social relationships. This network definition made it possible to examine current and stable network relationships and assisted in recruiting current members of a person's social network: both to ensure that the social

network analysis captured these relationships and to ensure that people identified as having influential relationships with others could be invited to participate in the study. However, the focus on current social network relationships, by design, excluded those relationships that were historical or more peripheral to the network members.

The networks reported in this study were also limited by issues of recruitment. Firstly, not everyone who was identified by the original participants was then willing or able to participate in the study, and also not all people who were significant may have been identified by participants. Additionally, not only were the social networks shaped by the inclusion criterion imposed by the researcher and institutional requirements (see methodology Chapter 2), the service that was selected in each site and the subsequent (and somewhat random) decision regarding who to recruit as the 'key individual' for each network in each study site also influenced how the networks were reported in this study. Those people who were more private about their injecting networks were deliberately excluded from the initial recruitment phases because of the research focus on networks, not individuals.

Social network data also introduces limitations related to the matching of important relationships and events. Due to the relatively small sizes of the networks reported in this study and observations obtained during data collection processes, the matching of relationships in this study was not a limitation. However, the ability to identify and subsequently link individual accounts to make assessments about social network influence, introduced a particularly unique dimension of this analysis. This linking could be limited by issues of recall or bias, particularly the identification (or exclusion) of the type of people, relationships and events, deemed relevant and discussed (or not) by the study participant in the research encounter (De Laine, 1997; Knoke & Yang, 2007; Lincoln & Guba, 1985; Wasserman & Faust, 1994). The use of a social network design also introduced some unique data management considerations, specifically the sheer volume of data that this study

produced. The volume of data was so large (possibly as large as three times that of a traditional thematic analysis of individual accounts) that a decision had to be made to not prepare and report a detailed analysis of the relational social network data collected in the North Coast area. However, as discussed, the data from the North Coast network was still included in the thematic analysis on peer distribution.

The social network design also revealed some important ethical considerations that are unique to this approach to conducting qualitative research. In all research involving humans, privacy and confidentiality is crucial in ensuring the ethical requirements of the study are met (Patton, 2002). However, social network analysis requires the collection of information about a person and their important relationships, and therefore identifying information is required to perform social network analysis. In this study it would not have been possible to collect and analyse this network data without knowing who people were and what relationships they had with each other. This created a particular ethical issue (or tension) when maintaining the privacy of study participants in this study. As all study participants were interviewed individually and no attempt was made to use knowledge gained from one interview as prompts for others or to corroborate individual accounts within the interview process, it was the data analysis process that confirmed or discounted social network influence, rather than these phenomenon being observed in, and reported by, the network members themselves.

Another ethical issue arose when the network data revealed names of people who did not participate in the study but who were identified and reported on in this network analysis. As there was no way of obtaining informed consent from people who did not participate in the study, accounts about non-participating network members were only included where this person was crucial in understanding the social context of the group and where the relationship was identified by more than one person in the network. Within the relational analyses, attention was drawn to the

reporting of accounts and events that were unable to be corroborated by the non-participating network member. Confidentiality and privacy issues related to non-participating network members was maintained by the allocation of pseudonyms, which were allocated to all participants in this study during the cleaning of study data.

Although social network-related insights were initiated through observing the interaction between different network members attending interviews, more detailed understandings of the complex network dynamics occurring within these groups could provide further insights into the influence of the social network if group-based data collection techniques were used, including observation. However, any consideration given to social network data collection techniques requires a clearer understanding of the ethical implications and dilemmas that this type of data collection may introduce. Given there was little prior research available to guide this approach taken to conducting a qualitative social network analysis, there is a clear need and opportunity for future research to more systematically examine social network factors that influence hepatitis C risk and prevention in a range of diverse injecting and social networks. The use of a qualitative approach to social network analysis generated new and interesting insights and therefore consideration should therefore be given to including a qualitative component in all large epidemiological social network studies in addition to qualitative social network analysis studies being conducted in their own right. Additionally, a more explicit focus on other network relationships, such as those on the periphery of networks, as well as longitudinal qualitative research designs could be considered. Ultimately, more research is needed to better understand how the social network (positively and negatively) influences hepatitis C transmission risk and prevention within social networks of PWID and it is hoped that this study will contribute to the further development of this field of research.

8.8 Concluding remarks

This study is one of the first to take a qualitative approach to social network analysis to document the examine understandings, communication and network dynamics regarding hepatitis C within specific networks of PWID. The qualitative social network approach employed in this study has highlighted that crucial knowledge can be gained by approaching social network analysis via a qualitative lens, particularly in research on injecting drug use and hepatitis C prevention. Most importantly, this approach was able to generate new insights about the social dynamics of injecting networks, which can inform our understanding of the ways in which hepatitis C-related harm, risk and vulnerability are influenced by and contingent upon social network relationships, an under-researched area within the micro-social level influence in hepatitis C transmission and prevention.

Although the networks recruited into this study were quite different with respect to network structure, membership, drug use and service access characteristics, as well as hepatitis C status, it was the similarities between these networks that have generated the most interesting insights. These findings highlight an extensive delay between the time when people first begin injecting and when they first come into contact with information about hepatitis C. Gaps and confusion regarding information about hepatitis C were also reported between these networks of PWID, and perhaps more importantly, knowledge differences were evident between some members of the same social network. This difference appeared to be directly influenced by a pervasive silence surrounding hepatitis C within these networks, as hepatitis C was viewed as unacceptable topic of discussion and one to be actively avoided in these social settings. Although hepatitis C was not openly discussed, the network members who took part in this study reported participating in network-based practices that could be seen to influence hepatitis C prevention and transmission. Peer distribution, the practice of distributing of sterile injecting equipment within populations of PWID, was an important practice that could be seen to create a more enabling environment for harm reduction, as this

practice had the ability to reduce the risk of hepatitis C transmission among networks of PWID. Whereas the network dynamics, including injecting hierarchies, network turnover and ability to challenge practice were reported in the study but not identified by network members as possible hepatitis C transmission risks, pointing to potential areas for further investigation.

Unlike other studies, which have found that PWID may not acknowledge, or be conscious of, the influence of environmental factors in hepatitis C transmission (Link & Phelan, 2006; Rhodes, 2002), the network members in this research were indeed conscious of, and even tried to respond to, a number of micro- and macro-level influences identified as directly impacting on their drug use and related hepatitis C transmission risk: albeit without openly discussing hepatitis C. These networks of PWID were consciously aware of and active in trying to create safe spaces (when possible) for themselves and their friends to inject. Permitting friends inject in one's home, combining resources to procure drugs, as well as providing general and emotional support were positive and protective features evident across all of the networks that took part in the research. These protective network factors were also accompanied by a strongly articulated requirement to always distribute sterile injecting equipment to friends when they needed it. Clearly locating responsibility for the distribution of injecting equipment within networks of PWID, five participants in this study had taken it upon themselves to distribute approximately 35,000 needles and syringes annually within their social networks: an extraordinary achievement. However, current responses to increasing the distribution of sterile injecting equipment have not been able to build upon these local practices of peer distribution because it is currently prohibited. Acknowledging the prevention efforts located in the everyday worlds of PWID requires more than legislative change: it is fundamental that PWID be perceived as active and legitimate actors in Australia's harm reduction efforts.

The relational data collected and analysed in this research has highlighted that social networks are complex and diverse and can directly influence hepatitis C risk and prevention. Overwhelmingly,

current hepatitis C prevention efforts focus on behavioural interventions that target the individual (Sacks-Davis, Horyniak, Grebely, & Hellard, 2012) and as noted previously, these current efforts therefore have little, or no, reference to the relationships that shape injecting episodes occurring in specific social contexts (Fraser et al., 2013; Winter et al., 2011). As a result, a disconnect operates between public health messages that aim to prevent hepatitis C transmission and the lived experience of PWID, and this has the potential to increase the transmission of hepatitis C (Bourgois, 1998; Bourgois et al., 2004; Dwyer et al., 2011; Fraser, 2013). Although numerous critiques of the individualistic focus of health promotion have been made (Bryant et al., 2010; Dwyer et al., 2011; Fraser, 2004; Treloar et al., 2008), including calls to create safer micro-social environments to prevent hepatitis C (Fraser, 2013; Fraser et al., 2013; Jackson et al., 2010; Rhodes, 2009; Rhodes & Treloar, 2008), the recommendations from these research studies have not yet been translated into policy and practice.

In addition, the political landscape in Australia is currently in flux and a number of recent national policy changes have the potential to increase social disadvantage and perpetuate health inequalities among populations of PWID. For example, from the 1st of January 2015, sixteen and seventeen year olds will no longer be eligible for federal assistance unless they are enrolled in further education, people under the age of 30 years of age will be required to wait six months before being eligible to receive unemployment benefits, and people under 25 years will no longer have access to unemployment benefits (Commonwealth of Australia, 2014). These changes will increase the economic marginalisation of young people, constrain agency and widen health and social inequalities, which will likely exacerbate the factors which influence the transmission of hepatitis C.

In summary, this research has demonstrated that the micro-social environment is an important and under-reported influence in the prevention and transmission of hepatitis C. However, if hepatitis C prevention efforts are to reach the intended target audience and are to be appropriate and

effective, hepatitis C research, policy and prevention efforts need to acknowledge, so as to understand and respond to, the different, diverse and complex relationships, interests, beliefs and practices that are present in networks of PWID (Carruthers, 2007; Rhodes, 2009), as well as acknowledging and legitimising existing network-based practices that have the ability to prevent hepatitis C within these network settings.

References

- Abelson, J., Treloar, C., Crawford, J., Kippax, S., Van Beek, I., & Howard, J. (2006). Some characteristics of early-onset injection drug users prior to and at the time of their first injection. *Addiction*, 101(4), 548-555.
- ACT Human Rights Commission. (2013). Legal Issues in Australian Public Health *A series of 7 papers on the impacts of discrimination and criminalisation on public health approaches to blood borne viruses and sexually transmissible infections*. Canberra.
- Adimora, A., & Schoenbach, V. (2005). Social context, sexual networks, and racial disparities in rates of sexually transmitted infections. *Journal of Infectious Diseases*, 191(Supplement 1), S115-S122.
- Ahern, J., Stuber, J., & Galea, S. (2007). Stigma, discrimination and the health of illicit drug users. *Drug and Alcohol Dependence*, 88(2-3), 188-196.
- Aitken, C., Higgs, P., & Bowden, S. (2008). Differences in the social networks of ethnic Vietnamese and non-Vietnamese injecting drug users and their implications for blood-borne virus transmission. *Epidemiology & Infection*, 136(03), 410-416.
- Aitken, C., Kerger, M., & Crofts, N. (2002). Peer-delivered hepatitis C testing and counselling: a means of improving the health of injecting drug users. *Drug and Alcohol Review*, 21(1), 33-37.
- Aitken, C., Lewis, J., Hocking, J., Bowden, D., & Hellard, M. (2009). Does Information about IDUs' Injecting Networks Predict Exposure to the Hepatitis C Virus? *Hepatitis Monthly*, 19(1), 17-23.
- Aitken, C., Moore, D., Higgs, P., Kelsall, J., & Kerger, M. (2002). The impact of a police crackdown on a street drug scene: evidence from the street. *International Journal of Drug Policy*, 13(3), 193-202.
- Alaszewski, A. (2005). Risk communication: identifying the importance of social context. *Health, Risk & Society*, 7(2), 101-105.
- Alexander, M. (2009). *Qualitative social network research for relational sociology*. Paper presented at the Paper presented to The Annual Conference of The Australian Sociological Association, Canberra, 1-4 December 2009.
- Alter, M. (2002). Prevention of spread of hepatitis C. *Hepatology*, 36(5B), s93-s98.
- Alter, M. (2007). Epidemiology of hepatitis C virus infection. *World Journal of Gastroenterology*, 13(17), 2436-2441.
- Amirkhanian, Y., Kelly, J., Kabakchieva, E., McAuliffe, T., & Vassileva, S. (2003). Evaluation of a social network HIV prevention intervention program for young men who have sex with men in Russia and Bulgaria. *AIDS Education and Prevention*, 15(3), 205-220.
- Amirkhanian, Y., Kelly, J., & McAuliffe, T. (2005). Identifying, recruiting, and assessing social networks at high risk for HIV/AIDS: methodology, practice, and a case study in St Petersburg, Russia. *AIDS Care*, 17(1), 58-75.

- Anderson, R., Clancy, L., Flynn, N., Kral, A., & Bluthenthal, R. (2003). Delivering syringe exchange services through “satellite exchangers”: the Sacramento Area Needle Exchange, USA. *International Journal of Drug Policy*, 14(5), 461-463.
- Anderson, S., McConville, S., & Neale, J. (2013). Evaluation of the development and delivery of the Peer to Peer Education Pilot among People Who Inject Drugs in Scotland. Scotland: NHS Scotland.
- Anti-Discrimination Board of NSW. (2001). C-change: the report of the enquiry into hepatitis C related discrimination Sydney: Anti-Discrimination Board of New South Wales.
- Aspinall, E., Corson, S., Doyle, J., Grebely, J., Hutchinson, S., Dore, G., . . . Hellard, M. (2013). Treatment of hepatitis C virus infection among people who are actively injecting drugs: a systematic review and meta-analysis. *Clinical infectious diseases*, 57(suppl 2), S80-S89.
- Aspinall, E., Weir, A., Sacks-Davis, R., Spelman, T., Grebely, J., Higgs, P., . . . Hellard, M. (2014). Does informing people who inject drugs of their hepatitis C status influence their injecting behaviour? Analysis of the Networks II study. *International Journal of Drug Policy*, 25(1), 179-182.
- Auerbach, J. (2009). Transforming social structures and environments to help in HIV prevention. *Health Affairs*, 28(6), 1655-1665.
- Australian Bureau of Statistics. (2006). *Year Book (Cat No 1301.0)*. Canberra: Australian Bureau of Statistics.
- Australian Bureau of Statistics. (2011a). *2011 Census of Population and Housing: Counts of Aboriginal and Torres Strait Islander Australians (Cat no 2075.0)* Canberra: Australian Bureau of Statistics.
- Australian Bureau of Statistics. (2011b). *2011 Census of Population and Housing: Demographic profile, City of Newcastle New South Wales (Cat no 2001.0)*. Canberra: Australian Bureau of Statistics,.
- Australian Bureau of Statistics. (2011c). *Census Quickstats*. Canberra: Australian Bureau of Statistics.
- Australian Bureau of Statistics. (2011d). *Regional Population Growth*. Canberra: Australian Bureau of Statistics.
- Australian Government Department of Health and Ageing. (2010a). National Needle and Syringe Programs Strategic Framework 2010-2014. Canberra: Commonwealth of Australia.
- Australian Government Department of Health and Ageing. (2010b). Third National Hepatitis C Strategy 2010-2013. Canberra: Commonwealth of Australia.
- Australian Illicit Injecting Drug Users League. (2009). A guide to cleaning used syringes: When there is no other way Canberra: Australian Illicit Injecting Drug Users League.
- Australian Injecting and Illicit Drug Users League. (2006). A framework for peer education by drug user organisations. Canberra: Australian Injecting and Illicit Drug Users League.
- Australian National Council on Drugs. (2006). Australia commemorates 20 years of needle syringe programs. Canberra: Australian National Council on Drugs.

- Australian National Council on Drugs. (2013). Needle and Syringe Programs *ANCD Position Paper*. Canberra: ANCD.
- Bacon, B., Gordon, S., Lawitz, E., Marcellin, P., Vierling, J., Zeuzem, S., . . . Boparai, N. (2011). Boceprevir for previously treated chronic HCV genotype 1 infection. *New England Journal of Medicine*, 364(13), 1207-1217.
- Bailey, S., Ouellet, L., Mackesy-Amity, M., Golub, E., Hagan, H., Hudson, S., . . . Garfein, R. (2007). Perceived risk, peer influences, and injection partner type predict receptive syringe sharing among young adult injection drug users in five US cities. *Drug and Alcohol Dependence*, 91, S18-S29.
- Balfour, L., Kowal, J., Corace, K., Tasca, G., Kryszanski, V., Cooper, C., & Garber, G. (2009). Increasing public awareness about hepatitis C: Development and validation of the brief hepatitis C knowledge scale. *Scandinavian Journal of Caring Sciences*, 23(4), 801-808.
- Beazley, H., & Ennew, J. (2006). Participatory methods and approaches: Tackling the two tyrannies. *Doing development research*, 189-199.
- Beletsky, L., Grau, L., White, E., Bowman, S., & Heimer, R. (2011). The roles of law, client race and program visibility in shaping police interference with the operation of US syringe exchange programs. *Addiction*, 106(2), 357-365.
- Benyo, A. (2006). Promoting secondary exchange: opportunities to advance public health. New York, NY: The Harm Reduction Coalition, Syringe Access Expansion Project.
- Berger, P., & Luckmann, T. (2011). *The social construction of reality: A treatise in the sociology of knowledge*: Open Road.
- Bernard, D., Kippax, S., & Baxter, D. (2008). Effective partnership and adequate investment underpin a successful response: key factors in dealing with HIV increases. *Sexual Health*, 5(2), 193-201.
- Biernacki, P., & Waldorf, D. (1981). Snowball sampling: Problems and techniques of chain referral sampling. *Sociological methods & research*, 10(2), 141-163.
- Blumer, H. (1986). *Symbolic interactionism: Perspective and method*: Univ of California Press.
- Borgatti, S., Mehra, A., Brass, D., & Labianca, G. (2009). Network analysis in the social sciences. *Science*, 323(5916), 892-895.
- Borgatti, S., & Molina, J. (2005). Toward ethical guidelines for network research in organizations. *Social Networks*, 27(2), 107-117.
- Bourdieu, P., & Wacquant, L. (1992). *Réponses: pour une anthropologie réflexive*: Seuil Paris.
- Bourgois, P. (1998). The moral economies of homeless heroin addicts: confronting ethnography, HIV risk, and everyday violence in San Francisco shooting encampments. *Substance Use & Misuse*, 33(11), 2323-2351.
- Bourgois, P., Lettiere, M., & Quesada, J. (1997). Social misery and the sanctions of substance abuse: Confronting HIV risk among homeless heroin addicts in San Francisco. *Social Problems*, 155-173.

- Bourgois, P., Prince, B., & Moss, A. (2004). The everyday violence of hepatitis C among young women who inject drugs in San Francisco. *Human organization*, 63(3), 253-264.
- Bourgois, P., & Schonberg, J. (2009). *Righteous dopefiend*: Univ of California Press.
- Bradshaw, D., Matthews, G., & Danta, M. (2013). Sexually transmitted hepatitis C infection: the new epidemic in MSM? *Current opinion in infectious diseases*, 26(1), 66-72.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77-101.
- Brener, L., Von Hippel, W., & Kippax, S. (2007). Prejudice among health care workers toward injecting drug users with hepatitis C: Does greater contact lead to less prejudice? *International Journal of Drug Policy*, 18(5), 381-387.
- Briggs, D., Rhodes, T., Marks, D., Kimber, J., Holloway, G., & Jones, S. (2009). Injecting drug use and unstable housing: Scope for structural interventions in harm reduction. *Drugs: Education, Prevention, and Policy*, 16(5), 436-450.
- Broadhead, R., Heckathorn, D., Weakliem, D., Anthony, D., Madray, H., Mills, R., & Hughes, J. (1998). Harnessing peer networks as an instrument for AIDS prevention: results from a peer-driven intervention. *Public Health Reports*, 113(Suppl 1), 42.
- Bryant, J. (2013). Using respondent-driven sampling with 'hard to reach' marginalised young people: problems with slow recruitment and small network size. *International Journal of Social Research Methodology*(ahead-of-print), 1-13.
- Bryant, J., Brener, L., Hull, P., & Treloar, C. (2010). Needle sharing in regular sexual relationships: An examination of serodiscordance, drug using practices, and the gendered character of injecting. *Drug and Alcohol Dependence*, 107(2), 182-187.
- Bryant, J., Ellard, J., Fisher, D., & Treloar, C. (2012). The exposure and transition study: exposure to injecting and hepatitis C among young people at risk (*Monograph 2/2012*). The University of New South Wales: National Centre in HIV Social Research.
- Bryant, J., & Hopwood, M. (2009). Secondary exchange of sterile injecting equipment in a high distribution environment: A mixed method analysis in south east Sydney, Australia. *International Journal of Drug Policy*, 20(4), 324-328.
- Bryant, J., Paquette, D., & Wilson, H. (2012). Syringe Coverage in an Australian Setting: Does a High Level of Syringe Coverage Moderate Syringe Sharing Behaviour? *AIDS and Behavior*, 16(5), 1156-1163.
- Bryman, A. (2012). *Social research methods*: OUP Oxford.
- Burris, S., Blankenship, K. M., Donoghoe, M., Sherman, S., Vernick, J. S., Case, P., . . . Koester, S. (2004). Addressing the "Risk Environment" for Injection Drug Users: The Mysterious Case of the Missing Cop. *Milbank Quarterly*, 82(1), 125-156.
- Burrows, D. (2006). Rethinking coverage of needle exchange programs. *Substance Use & Misuse*, 41(6-7), 1045-1048.

- Burt, R., Thiede, H., & Hagan, H. (2009). Serosorting for hepatitis C status in the sharing of injection equipment among Seattle area injection drug users. *Drug and Alcohol Dependence*, 105(3), 215-220.
- Butler, T., Lim, D., & Callander, D. (2011). National Prison Entrants' Bloodborne Virus & Risk Behaviour Survey 2004, 2007, and 2010: Prevalence of HIV, HBV, HCV and risk behaviours among Australian prison entrants: national report. Sydney: Kirby Institute, UNSW.
- Butt, G. (2008). Stigma in the context of hepatitis C: Concept analysis. *Journal of Advanced Nursing*, 62(6), 712-724.
- Butt, G., Paterson, B., & McGuinness, L. (2008). Living with the stigma of hepatitis C. *Western Journal of Nursing Research*, 30(2), 204-221.
- Canadian HIV/AIDS Legal Network. (2005). Nothing About Us Without Us; Greater Meaningful involvement of People Who Use Illegal Drugs: A Public Health, Ethical and Human Rights Imperative. Toronto, Canada: Canadian HIV/AIDS Legal Network, .
- Carey, J., Perlman, D., Friedmann, P., Kaplan, W., Nugent, A., Deutscher, M., . . . Des Jarlais, D. (2005). Knowledge of hepatitis among active drug injectors at a syringe exchange program. *Journal of Substance Abuse Treatment*, 29(1), 47-53.
- Carpentier, N., & Ducharme, F. (2007). Social network data validity: the example of the social network of caregivers of older persons with Alzheimer-type dementia. *Canadian Journal on Aging/La Revue canadienne du vieillissement*, 26(S1), 103-115.
- Carrier, N., Laplante, J., & Bruneau, J. (2005). Exploring the contingent reality of biomedicine: Injecting drug users, hepatitis C virus and risk *Health, Risk & Society*, 7(2), 123-140.
- Carruthers, S. (2003). Hepatitis C and Novice Injecting Drug Users. Monograph No. 6. Perth, Western Australia: Curtin University of Technology. National Drug Research Institute,.
- Carruthers, S. (2005). Preventing hepatitis C: what do positive injectors do? *Drug and Alcohol Review*, 24(2), 193-198.
- Carruthers, S. (2007). The Organization of a Community:Community-Based Prevention of Injecting Drug Use-Related Health Problems. *Substance use & misuse*, 42(12-13), 1971-1977.
- Casey, L., & McGregor, H. (2012). A critical examination of experiential knowledge in illicit substance use research and policy. *J Addict Res Ther*, 3(5), 1-9.
- Cepeda, J., Odinkova, V., Heimer, R., Grau, L., Lyubimova, A., Safiullina, L., . . . Niccolai, L. (2011). Drug network characteristics and HIV risk among injection drug users in Russia: The roles of trust, size, and stability. *AIDS and Behavior*, 15(5), 1003-1010.
- Chen, S., & Morgan, T. (2006). The natural history of hepatitis C virus (HCV) infection. *International journal of medical sciences*, 3(2), 47-52.
- Choo, Q.-L., Kuo, G., Weiner, A., Overby, L., Bradley, D., & Houghton, M. (1989). Isolation of a cDNA Clone Derived from a Blood-Borne Non-A, Non-B Viral Hepatitis Genome. *Science*, 244(4902), 359-362.

- City of Newcastle. (2011). Newcastle Voice Social Planning Consultation Report. Newcastle: City of Newcastle Council.
- City of Sydney Council. (2011). The City of Sydney Street Count, : City of Sydney Council.
- Cohen, J. (1999). L'hépatite C, infection silencieuse et bombe à retardement. *La Recherche*(325), 68-74.
- Commonwealth of Australia. (2004). Newcastle Earthquake: Geoscience Australia.
- Commonwealth of Australia. (2010). National Needle and Syringe Program National Strategic Framework 2010-2014. Canberra: Commonwealth of Australia.
- Commonwealth of Australia. (2011). National Drug Strategy 2010-2015. Canberra: Commonwealth of Australia.
- Commonwealth of Australia. (2014). Budget 2014-15: Increasing the age of eligibility for Newstart Allowance and Sickness Allowance. Retrieved from <http://www.humanservices.gov.au/corporate/publications-and-resources/budget/1415/measures/young-people-and-students/53-11122>
- Cook, J., Purdie-Vaughns, V., Meyer, I., & Busch, J. (2014). Intervening within and across levels: A multilevel approach to stigma and public health. *Social Science & Medicine*, 103, 101-109.
- Cook, K., & Whitmeyer, J. (1992). Two approaches to social structure: Exchange theory and network analysis. *Annual Review of Sociology*, 109-127.
- Costenbader, E. C., Astone, N. M., & Latkin, C. A. (2006). The dynamics of injection drug users' personal networks and HIV risk behaviors. *Addiction*, 101(7), 1003-1013.
- Coupland, H., Maher, L., & Ritchie, J. (2004). Within reach: A participatory needs assessment of young injecting drug users in South Western Sydney. . Sydney: University of New South Wales.
- Cox, A., & Thomas, D. (2013). Hepatitis C virus vaccines among people who inject drugs. *Clinical infectious diseases*, 57(suppl 2), S46-S50.
- Cox, J., De, P., Morissette, C., Tremblay, C., Stephenson, R., Allard, R., . . . Roy, É. (2008). Low perceived benefits and self-efficacy are associated with hepatitis C virus (HCV) infection-related risk among injection drug users. *Social science & medicine*, 66(2), 211-220.
- Craine, N., Hickman, M., Parry, J., Smith, J., Walker, M., & Nix, B. (2008). *HCV incidence amongst drug injectors: The effect of opiate substitution treatment and homelessness*. Paper presented at the International Conference on the Reduction of Drug-Related Harm, Barcelona.
- Crawford, M., & Marecek, J. (1989). Feminist theory, feminist psychology: A bibliography of epistemology, critical analysis, and applications. *Psychology of Women Quarterly*, 13(4), 477-491.
- Crofts, N., & Louie, R. (1997). The next plague: stigmatization and discrimination related to hepatitis C virus infection in Australia. *Health and Human Rights*, 2(2), 86-97.

- Crossley, N. (2010). The Social World of the Network. Combining Qualitative and Quantitative Elements in Social Network Analysis. *Sociologica*, 4(1), 0-0.
- Davey-Rothwell, M., & Latkin, C. (2007). Gender Differences in Social Network Influence among Injection Drug Users: Perceived Norms and Needle Sharing. *Journal of Urban Health*, 84(5), 691-703.
- Davis, M., & Rhodes, T. (2004). Beyond prevention? Injecting drug user narratives about hepatitis C. *International Journal of Drug Policy*, 15(2), 123-131.
- Day, C., Jayasuriya, R., & Stone, G. (2004). Hepatitis C-related discrimination in New South Wales. *Australian Health Review*, 27(2), 57-60.
- Day, C., Ross, J., & Dolan, K. (2003). Hepatitis C-related discrimination among heroin users in Sydney: drug user or hepatitis C discrimination? *Drug and Alcohol Review*, 22(3), 317-321.
- De Laine, M. (1997). *Ethnography: Theory and applications in health research*: MacLennan & Petty.
- De, P., Cox, J., Boivin, J.-F., Platt, R., & Jolly, A. (2008). Social network-related risk factors for bloodborne virus infections among injection drug users receiving syringes through secondary exchange. *Journal of Urban Health*, 85(1), 77-89.
- De, P., Cox, J., Boivin, J., -F., Platt, R., & Jolly, A. (2007). The importance of social networks in their association to drug equipment sharing among injection drug users: a review. *Addiction*, 102(11), 1730-1739.
- DeBeck, K., Shannon, K., Wood, E., Li, K., Montaner, J., & Kerr, T. (2007). Income generating activities of people who inject drugs. *Drug and Alcohol Dependence*, 91(1), 50-56.
- DeBeck, K., Wood, E., Qi, J., Fu, E., McArthur, D., Montaner, J., & Kerr, T. (2011). Interest in low-threshold employment among people who inject illicit drugs: Implications for street disorder. *International Journal of Drug Policy*, 22(5), 376-384.
- Denzin, N., & Lincoln, Y. (2000). The discipline and practice of qualitative research. *Handbook of qualitative research*, 2, 1-28.
- Dienstag, J. (2003). Sexual and perinatal transmission of hepatitis C. *Hepatology*, 26(S3), 66S-70S.
- Dieperink, E., Ho, S., Tetrack, L., Thuras, P., Dua, K., & Willenbring, M. (2004). Suicidal ideation during interferon- α 2b and ribavirin treatment of patients with chronic hepatitis C. *General hospital psychiatry*, 26(3), 237-240.
- Dixon, D., & Coffin, P. (1999). 'Zero tolerance policing of illegal drug markets'. *Drug and Alcohol Review*, 18(4), 477 - 486.
- Doab, A., Treloar, C., & Dore, G. (2005). Knowledge and Attitudes about Treatment for Hepatitis C Virus Infection and Barriers to Treatment among Current Injection Drug Users in Australia. *Clinical Infectious Diseases*, 40(Supplement 5), S313-S320.
- Dore, G. (2001). Natural history of hepatitis C virus infection. In N. Crofts, G. Dore & S. A. Locarnini (Eds.), *Hepatitis C: An Australian perspective*. East Hawthorne: IP Communications.

- Dore, G. (2012). The changing therapeutic landscape for hepatitis C. *The Medical Journal of Australia*, 196(10), 629-632.
- Douglas, B., & McDonald, D. (2012). The prohibition of illicit drugs is killing and criminalising our children and we are letting it happen: report of a high level Australia21 roundtable. Canberra: Australia21.
- Douglas, B., Wodak, A., & McDonald, D. (2012). Alternatives to Prohibition illicit drugs: How we can stop killing and criminalising young Australians *Report of the second Australia21 Roundtable on Illicit Drugs held at The University of Melbourne on 6 July 2012*. Weston ACT: Australia 21 Limited.
- Douglas, M. (2013). *Risk and blame*. New York: Routledge.
- Duff, C. (2003). The importance of culture and context: Rethinking risk and risk management in young drug using populations. *Health, Risk & Society*, 5(3), 285-299.
- Duff, C. (2010). Enabling places and enabling resources: New directions for harm reduction research and practice. *Drug and Alcohol Review*, 29(3), 337-344.
- Duff, C. (2011). Networks, resources and agencies: On the character and production of enabling places. *Health & Place*, 17(1), 149-156.
- Duffin, J. (2005). *Lovers and livers: Disease concepts in history*: University of Toronto Press.
- Dunn, J. (2000). Housing and health inequalities: review and prospects for research. *Housing Studies*, 15(3), 341-366.
- Dwyer, R., Fraser, S., & Treloar, C. (2011). Doing things together? Analysis of health education materials to inform hepatitis C prevention among couples. *Addiction Research & Theory*, 19(4), 352-361.
- Economic Intelligence Unit. (2013). Hepatitis C: Taking a Serious Problem Seriously report.
- Emerson, R. (1976). Social exchange theory. *Annual Review of Sociology*, 2, 335-362.
- Emirbayer, M., & Goodwin, J. (1994). Network analysis, culture, and the problem of agency. *American journal of sociology*, 1411-1454.
- Emiroglu, N. (2010). *Viral Hepatitis Burden and Policy Directions in the European Region of WHO*. Paper presented at the Summit Conference on Hepatitis B and C, Brussels.
- Emmel, N., & Clarke, A. (2009). The methods used in Connected Lives: Investigating networks, neighbourhoods and communities, Real life methods *Economic & Social Research Council*. Manchester: ESRC National Centre for Research Methods.
- European Monitoring Centre for Drugs and Drug Addiction. (2011). Drug Policy Profiles: Portugal. Lisbon: European Monitoring Centre for Drugs and Drug Addiction.
- Evans, J., Hahn, J., Page-Shafer, K., Lum, P., Stein, E., Davidson, P., & Moss, A. (2003). Gender differences in sexual and injection risk behavior among active young injection drug users in San Francisco (the UFO Study). *Journal of Urban Health*, 80(1), 137-146.

- Farmer, P. (2009). On suffering and structural violence: a view from below. *Race/Ethnicity: Multidisciplinary Global Contexts*, 3(1), 11-28.
- Ferrer-Castro, V., Crespo-Leiro, M., García-Marcos, L., Pérez-Rivas, M., Alonso-Conde, A., García-Fernández, I., . . . Sanjosé-Vallejo, R. (2012). Evaluation of needle exchange program at Pereiro de Aguiar prison (Ourense, Spain): ten years of experience]. *Revista española de sanidad penitenciaria*, 14(1), 3.
- Fickling, D. (2010). Hunter Ports plans \$2.5bn coal terminal at Newcastle port, *The Australian*. Retrieved from <http://www.theaustralian.com.au/business/mining-energy/hunter-ports-plans-25bn-coal-terminal-at-newcastle-port/story-e6frg9df-1226209308038>
- Fisher, D., Wilson, H., & Bryant, J. (2013). Harm reduction knowledge and information exchange among secondary distributors in Sydney, Australia. *Drugs: education, prevention and policy*, 20(1), 67-73.
- Fitzgerald, J., McDonald, K., & Klugman, M. (2004). Unspoken but everpresent: Hepatitis C in a regional setting. Melbourne: The Centre for the Study of Health and Society and The Sociology Program, The University of Melbourne.
- Fraser, S. (2004). 'It's your life!': injecting drug users, individual responsibility and hepatitis C prevention. *Health*, 8(2), 199-221.
- Fraser, S. (2013). The missing mass of morality: A new fitpack design for hepatitis C prevention in sexual partnerships. *International Journal of Drug Policy*, 24(3), 212-219.
- Fraser, S., & Seear, K. (2011). *Making disease, making citizens: The politics of hepatitis C*. Ashgate: Aldershot.
- Fraser, S., & Treloar, C. (2006). 'Spoiled identity' in hepatitis C infection: The binary logic of despair. *Critical Public Health*, 16(2), 99-110.
- Fraser, S., Treloar, C., Bryant, J., & Rhodes, T. (2013). Hepatitis C prevention education needs to be grounded in social relationships. *Drugs: education, prevention and policy*, 21(1), 88-92.
- Freeman, A., Dore, G., Law, M., Thorpe, M., Von Overbeck, J., Lloyd, A., . . . Kaldor, J. (2001). Estimating progression to cirrhosis in chronic hepatitis C virus infection. *HEPATOLOGY*, 34(4), 809-816.
- Freeman, K., Jones, C., Weatherburn, D., Rutter, S., Spooner, C., & Donnelly, N. (2005). The impact of the Sydney medically supervised injecting centre (MSIC) on crime. *Drug and Alcohol Review*, 24(2), 173-184.
- Friedman, S. (1999). *Social networks, drug injectors' lives, and HIV/AIDS*: Kluwer Academic Pub.
- Friedman, S., & Aral, S. (2001). Social Networks, Risk-Potential Networks, Health, and Disease. *Journal of Urban Health*, 78(3), 411-418.
- Friedman, S., Curtis, R., Neaigus, A., Jose, B., & Des Jarlais, D. (1999). *Social networks, drug injectors' lives, and HIV/AIDS*: Springer.
- Friedman, S., de Jong, W., Rossi, D., Touzé, G., Rockwell, R., Des Jarlais, D., & Elovich, R. (2007). Harm reduction theory: Users' culture, micro-social indigenous harm reduction, and the self-

- organization and outside-organizing of users' groups. *International Journal of Drug Policy*, 18(2), 107-117.
- Friedman, S., Sandoval, M., Mateu-Gelabert, P., Meylakh, P., & Des Jarlais, D. (2011). Symbiotic goals and the prevention of blood-borne viruses among injection drug users. *Substance Use & Misuse*, 46(2-3), 307-315.
- Friedman, S. R., Maslow, C., Bolyard, M., Sandoval, M., Mateu-Gelabert, P., & Neaigus, A. (2004). Urging others to be healthy: "Intravention" by injection drug users as a community prevention goal. *AIDS Education and Prevention*, 16(3), 250-263.
- Fry, C., & Dwyer, R. (2001). For love or money? An exploratory study of why injecting drug users participate in research. *Addiction*, 96(9), 1319-1325.
- Fry, C., Treloar, C., & Maher, L. (2005). Ethical challenges and responses in harm reduction research: promoting applied communitarian ethics. *Drug and Alcohol Review*, 24(5), 449-459.
- Galea, S., & Vlahov, D. (2002). Social determinants and the health of drug users: socioeconomic status, homelessness, and incarceration. *Public health reports*, 117(Suppl 1), S135.
- Garfein, R., Golub, E., Greenberg, A., Hagan, H., Hanson, D., Hudson, S., . . . Purcell, D. (2007). A peer-education intervention to reduce injection risk behaviors for HIV and hepatitis C virus infection in young injection drug users. *AIDS*, 21(14), 1923.
- Gillies, M., Palmateer, N., Hutchinson, S., Ahmed, S., Taylor, A., & Goldberg, D. (2010). The provision of non-needle/syringe drug injecting paraphernalia in the primary prevention of HCV among IDU: a systematic review. *BMC public health*, 10(1), 721.
- Global Commission on Drug Policy. (2011). War on Drugs: report of the Global Commission on Drug Policy. Rio de Janeiro: Global Commission on Drugs.
- Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity*: Touchstone.
- Granovetter, M. (1983). The strength of weak ties: A network theory revisited. *Sociological theory*, 1(1), 201-233.
- Grant, R., & Sugarman, J. (2004). Ethics in human subjects research: do incentives matter? *Journal of Medicine and Philosophy*, 29(6), 717-738.
- Gray, R. (2009). The dynamics of shame: implications for counsellors working in alcohol and other drug settings. *Psychotherapy in Australia*, 16(1), 30-36.
- Gray, R. (2010). Shame, labeling and stigma: Challenges to counseling clients in alcohol and other drug settings. *Contemp. Drug Probs.*, 37, 685-704.
- Grebely, J., Conway, B., Raffa, J. D., Lai, C., Krajden, M., & Tyndall, M. W. (2006). Hepatitis C virus reinfection in injection drug users. *Hepatology*, 44(5), 1139-1145.
- Grebely, J., & Dore, G. (2011a). Prevention of hepatitis C virus in injecting drug users: a narrow window of opportunity. *Journal of Infectious Diseases*, 203(5), 571-574.
- Grebely, J., & Dore, G. (2011b). *What is killing people with hepatitis C virus infection?* Paper presented at the Seminars in Liver Diseases.

- Griffith, G. (2001). *Police Powers and Law Enforcement in New South Wales*. Sydney: Retrieved from [http://www.parliament.nsw.gov.au/prod/parlment/publications.nsf/0/c63026718e87aa35ca256ecf00084ac4/\\$FILE/11-01.pdf](http://www.parliament.nsw.gov.au/prod/parlment/publications.nsf/0/c63026718e87aa35ca256ecf00084ac4/$FILE/11-01.pdf).
- Griffiths, P., Gossop, M., Powis, B., & Strang, J. (1993). Reaching hidden populations of drug users by privileged access interviewers: methodological and practical issues. *Addiction*, 88(12), 1617-1626.
- Grund, J.-P., Friedman, S., Stern, L., Jose, B., Neaigus, A., Curtis, R., & Des Jarlais, D. (1996). Syringe-mediated drug sharing among injecting drug users: patterns, social context and implications for transmission of blood-borne pathogens. *Social Science & Medicine*, 42(5), 691-703.
- Grundy, G., & Beeching, N. (2003). Understanding social stigma in women with hepatitis C. *Nursing standard (Royal College of Nursing (Great Britain): 1987)*, 19(4), 35-39.
- Guba, E., & Lincoln, Y. (1994). Competing paradigms in qualitative research. *Handbook of qualitative research*, 2, 163-194.
- Guest, G., Bunce, A., & Johnson, L. (2006). How many interviews are enough? An experiment with data saturation and variability. *Field methods*, 18(1), 59-82.
- Gupta, L., Shah, S., & Ward, J. (2006). Educational and health service needs of Australian general practitioners in managing hepatitis C. *Journal of gastroenterology and hepatology*, 21(4), 694-699.
- Gyarmathy, V., Neaigus, A., Ujhelyi, E., Szabó, T., & Rácz, J. (2006). Strong HIV and hepatitis disclosure norms and frequent risk behaviors among Hungarian drug injectors. *Drug and Alcohol Dependence*, 82(S1), S65-S69.
- Habib, S. (2003). Understanding the context of risk practices among injecting drug users: Implications for hepatitis C prevention. *Australian Journal of Social Issues, The*, 38(1), 1-17.
- Habib, S., & Adorjany, L. (2003). Hepatitis C and injecting drug use: The realities of stigmatisation and discrimination. *Health Education Journal*, 62(3), 256-265.
- Hagan, H., Pouget, E., & Des Jarlais, D. (2011). A systematic review and meta-analysis of interventions to prevent hepatitis C virus infection in people who inject drugs. *Journal of Infectious Diseases*, 204(1), 74-83.
- Hagan, H., Thiede, H., & Des Jarlais, D. (2004). Hepatitis C virus infection among injection drug users: survival analysis of time to seroconversion. *Epidemiology*, 15(5), 543-549.
- Hahn, J., Evans, J., Davidson, P., Lum, P., & Page, K. (2010). Hepatitis C virus risk behaviors within the partnerships of young injecting drug users. *Addiction*, 105(7), 1254-1264.
- Hahn, J., Page-Shafer, K., Lum, P., Bourgois, P., Stein, E., Evans, J., . . . Moss, A. (2002). Hepatitis C virus seroconversion among young injection drug users: relationships and risks. *Journal of Infectious Diseases*, 186(11), 1558-1564.
- Harris, M. (2005). Living with hepatitis C: The medical encounter. *New Zealand Sociology* 20(1), 4-19.
- Harris, M., & Rhodes, T. (2013a). Hepatitis C treatment access and uptake for people who inject drugs: a review mapping the role of social factors. *Harm Reduction Journal*, 10(7).

- Harris, M., & Rhodes, T. (2013b). Injecting practices in sexual partnerships: Hepatitis C transmission potentials in a 'risk equivalence' framework. *Drug and Alcohol Dependence*.
- Harris, M., Treloar, C., & Maher, L. (2012). Staying Safe From Hepatitis C Engaging With Multiple Priorities. *Qualitative Health Research*, 22(1), 31-42.
- Harsch, H., Pankiewicz, J., Bloom, A., Rainey, C., Cho, J., Sperry, L., & Stein, E. (2000). Hepatitis C virus infection in cocaine users—a silent epidemic. *Community Mental Health Journal*, 36(3), 225-233.
- Hassan, E. (2006). Recall bias can be a threat to retrospective and prospective research designs. *The Internet Journal of Epidemiology*, 3(2), 339-412.
- Heckathorn, D. (1997). Respondent-driven sampling: a new approach to the study of hidden populations. *Social problems*, 44(2), 174-199.
- Heckathorn, D., Broadhead, R., Anthony, D., & Weakliem, D. (1999). AIDS and social networks: HIV prevention through network mobilization. *Sociological Focus*, 32(2), 159-179.
- Heimer, R., Clair, S., Grau, L., Bluthenthal, R., Marshall, P., & Singer, M. (2002). Hepatitis-associated knowledge is low and risks are high among HIV-aware injection drug users in three US cities. *Addiction*, 97(10), 1277-1287.
- Hellard, M., & Doyle, J., . (2014). Interferon-free hepatitis C treatment: one pill to fit all? *The Lancet*, 383(9916), 491-492.
- Hellard, M., Nguyen, O., Guy, R., Jardine, D., Mijch, A., & Higgs, P. (2006). The prevalence and risk behaviours associated with the transmission of blood-borne viruses among ethnic-Vietnamese injecting drug users. *Australian and New Zealand Journal of Public Health*, 30(6), 519-525.
- Hellard, M., Nguyen, O., Higgs, P., Guy, R., & Mijch, A. (2005). Blood borne viruses in ethnic Vietnamese IDUs: A report on the prevalence and risk behaviours associated with the transmission of blood borne viruses among ethnic Vietnamese injecting drug users (IDUs) in Victoria In U. report) (Ed.). Melbourne: The Burnett Institute.
- Hersberger, J. (2003). A qualitative approach to examining information transfer via social networks among homeless populations. *The New Review of Information Behaviour Research*, 4(1), 95-108.
- Higgs, P., Nguyen, Q., Ezard, N., & Crofts, N. (1999). Heroin use and the Vietnamese community: Is it a public health crisis? In P. Rice (Ed.), *Living in a new country: Understanding migrant health issues* (pp. 181-195). Melbourne: Ausmed.
- Hoffmann, J. P., Su, S. S., & Pach, A. (1997). Changes in network characteristics and HIV risk behavior among injection drug users. *Drug and alcohol dependence*, 46(1-2), 41-51.
- Holmberg, S., Ly, K., Kleven, M., Jiles, R., Xing, J., & Ward, J. (2012). *The growing burden of mortality associated with viral hepatitis in the United States, 1999-2007*. Paper presented at the AASLD 2011 Annual Meeting.
- Holstein, J., & Gubrium, J. (2007). Constructionist Perspectives on the Life Course. *Sociology Compass*, 1(1), 335-352.

- Holstein, J., & Gubrium, J. (2008). The constructionist mosaic. In J. Holstein & J. Gubrium (Eds.), *Handbook of constructionist research*. New York: The Guilford Press.
- Hopwood, M. (2013). Perspectives of a self-selected sample of former patients on the long-term health outcomes of interferon-based hepatitis C treatments: an exploratory study. *Psychology, Health & Medicine*, 1-9.
- Hopwood, M., Brener, L., & Wilson, H. (2012). Vaccine, transmission and treatment: An exploratory study of viral hepatitis knowledge among attendees of a metropolitan Australian university. *Drugs: education, prevention and policy*, 19(4), 346-350.
- Hopwood, M., Nakamura, T., & Treloar, C. (2010). Disclosing Hepatitis C Infection Within Everyday Contexts Implications for Accessing Support and Healthcare. *Journal of Health Psychology*, 15(6), 811-818.
- Hopwood, M., & Southgate, E. (2003). Living with hepatitis C: A sociological review. *Critical Public Health*, 13(3), 251-267.
- Hopwood, M., & Treloar, C. (2003). The 3D Project: Diagnosis, disclosure, discrimination and living with hepatitis C. UNSW: Sydney: National Centre in HIV Social Research.
- Hopwood, M., & Treloar, C. (2006). Experiences of hepatitis C treatment and its management *National Centre in HIV Social Research*. Sydney: University of New South Wales.
- Hopwood, M., Treloar, C., & Bryant, J. (2006). Hepatitis C and injecting-related discrimination in New South Wales, Australia. *Drugs: Education, Prevention, and Policy*, 13(1), 61-75.
- Hu, K.-Q., Kyulo, N., Esrailian, E., Thompson, K., Chase, R., Hillebrand, D., & Runyon, B. (2004). Overweight and obesity, hepatic steatosis, and progression of chronic hepatitis C: a retrospective study on a large cohort of patients in the United States. *Journal of Hepatology*, 40(1), 147-154.
- Hughes, C., & Stevens, A. (2012). A resounding success or a disastrous failure: Re-examining the interpretation of evidence on the Portuguese decriminalisation of illicit drugs. *Drug and Alcohol Review*, 31(1), 101-113.
- Huo, D., Bailey, S., Hershow, R., & Ouellet, L. (2005). Drug use and HIV risk practices of secondary and primary needle exchange users *AIDS Education and Prevention*, 17(2), 170-184.
- Hutchinson, S., Bird, S., & Goldberg, D. (2005). Influence of alcohol on the progression of hepatitis C virus infection: a meta-analysis. *Clinical Gastroenterology and Hepatology*, 3(11), 1150-1159.
- Inciardi, J., & Harrison, L. (2000). Introduction: the concept of harm reduction *Harm Reduction: National and International Perspectives*. Thousand Oaks, CA: Sage Publications (pp. 2-19).
- International Harm Reduction Association. (2010). What is Harm Reduction? A position statement from the International Harm Reduction Association. Retrieved from IHRA Briefing website: http://www.ihra.net/files/2010/08/10/Briefing_What_is_HR_English.pdf
- Irwin, K., & Fry, C. (2007). Strengthening drug policy and practice through ethics engagement: an old challenge for a new harm reduction. *International Journal of Drug Policy*, 18(2), 75-83.

- Irwin, K., Karchevsky, E., Heimer, R., & Badrieva, L. (2006). Secondary syringe exchange as a model for HIV prevention programs in the Russian Federation. *Substance Use & Misuse*, 41(6-7), 979-999.
- Islam, M., Day, C., & Conigrave, K. (2010). Harm reduction healthcare: From an alternative to the mainstream platform? *International Journal of Drug Policy*, 21(2), 131-133.
- Iversen, J., Grebely, J., Topp, L., Wand, H., Dore, G., & Maher, L. (2014). Uptake of hepatitis C treatment among people who inject drugs attending Needle and Syringe Programs in Australia, 1999–2011. *Journal of viral hepatitis*, 21(3), 198-207.
- Iversen, J., & Maher, L. (2013). Australian Needle and Syringe Program National Data Report 2008 – 2012: Prevalence of HIV, HCV and injecting and sexual behaviour among NSP attendees. In T. K. Institute (Ed.). Sydney, NSW: University of New South Wales.
- Jackson, L., Bailey, D., Fraser, J., Johnson, J., Currie, A., & Babineau, D. (2002). Safer and unsafe injection drug use and sex practices among injection drug users in Halifax, Nova Scotia. An exploratory look at community and interpersonal influences. *Canadian journal of public health. Revue canadienne de sante publique*, 93(3), 219-222.
- Jackson, L., Parker, J., Dykeman, M., Gahagan, J., & Karabanow, J. (2010). The power of relationships: Implications for safer and unsafe practices among injection drug users. *Drugs: Education, Prevention, and Policy*, 17(3), 189-204.
- Janke, E., McGraw, S., Garcia-Tsao, G., & Fraenkel, L. (2008). Psychosocial issues in hepatitis C: a qualitative analysis. *Psychosomatics*, 49(6), 494-501.
- Jennings, C., & Sherman, K. (2012). Hepatitis C and HIV Co-Infection: New Drugs in Practice and in the Pipeline. *Current HIV/AIDS Reports*, 1-7.
- Johnson, J. (1998). Research design and research strategies. *Handbook of methods in cultural anthropology*, 1, 131-171.
- Joint United Nations Programme on HIV/AIDS. (2011). Harm reduction for people who inject drugs. Retrieved from http://www.unaids.org/en/media/unaids/contentassets/documents/programmes/programmeffectivenessandcountrysupportdepartment/gfresourcekit/20110818_Technical_Guidance_Harm_Reduction.pdf
- Jürgens, R. (2005). "Nothing about us without us"-greater, meaningful involvement of people who use illegal drugs: a public health, ethical, and human rights imperative: Canadian HIV/AIDS Legal Network.
- Kelly, B. (2010). Sampling and recruitment issues in qualitative drugs research: Reflections on the study of club drug users in metro New York. *Substance use & misuse*, 45(5), 671-683.
- Kelsall, J., Higgs, P., Lam, T., & Crofts, N. (1998). The Vietnamese injecting drug use and harm reduction study. . Melbourne: The Centre for Harm reduction, Macfarlane Burnet Centre for Medical Research.
- Kerr, T., Small, W., & Wood, E. (2005). The public health and social impacts of drug market enforcement: A review of the evidence. *International Journal of Drug Policy*, 16(4), 210-220.

- Kim, A., & Page, K. (2013). Hepatitis C Virus Serosorting in People Who Inject Drugs: Sorting Out the Details. *Journal of Infectious Diseases*, 208(12), 1929-1931.
- Kim, C., Kerr, T., Li, K., Zhang, R., Tyndall, M., Montaner, J., & Wood, E. (2009). Unstable housing and hepatitis C incidence among injection drug users in a Canadian setting. *BMC Public Health*, 9(1), 270.
- Kimber, J., Mattick, R., Kaldor, J., & van Beek, I. (2008). Process and predictors of drug treatment referral and referral uptake at the Sydney Medically Supervised Injecting Centre. *Drug and Alcohol Review*, 27(6), 602-612.
- Klee, H., Faugier, J., Hayes, C., Boulton, T., & Morris, J. (1990). Factors associated with risk behaviour among injecting drug users. *AIDS care*, 2(2), 133-145.
- Klevens, R., Hu, D., Jiles, R., & Holmberg, S. (2012). Evolving Epidemiology of Hepatitis C Virus in the United States. *Clinical Infectious Diseases*, 55(suppl 1), S3-S9.
- Knoke, D., & Yang, S. (2007). *Social network analysis* (Vol. 154): SAGE Publications, Incorporated.
- Krieger, N. (2001). A glossary for social epidemiology. *Journal of Epidemiology and Community Health*, 55(10), 693-700.
- Kuyper, L., Kerr, T., Li, K., Hogg, R., Tyndall, M., Montaner, J., & Wood, E. (2006). Factors associated with buying and selling syringes among injection drug users in a setting of one of North America's largest syringe exchange programs. *Substance Use & Misuse*, 41(6-7), 883-899.
- Kwon, J., Anderson, J., Kerr, C., Thein, H., Zhang, L., Iversen, J., . . . Maher, L. (2012). Estimating the cost-effectiveness of needle-syringe programs in Australia. *AIDS*, 26(17), 2201-2210.
- Kwon, J., Iversen, J., Maher, L., Law, M., & Wilson, D. (2009). The Impact of Needle and Syringe Programs on HIV and HCV Transmissions in Injecting Drug Users in Australia: A Model-Based Analysis. *JAIDS Journal of Acquired Immune Deficiency Syndromes*, 51(4), 462-469.
- Latkin, C., Forman, V., Knowlton, A., & Sherman, S. (2003). Norms, social networks, and HIV-related risk behaviors among urban disadvantaged drug users. *Social Science & Medicine*, 56(3), 465-476.
- Latkin, C., Hua, W., Davey, M., & Sherman, S. (2003). Direct and indirect acquisition of syringes from syringe exchange programmes in Baltimore, Maryland, USA. *International Journal of Drug Policy*, 14(5), 449-451.
- Latkin, C., & Knowlton, A. (2005). Micro-social structural approaches to HIV prevention: a social ecological perspective. *AIDS Care*, 17(S1), 102-113.
- Latkin, C., Kuramoto, S., Davey-Rothwell, M., & Tobin, K. (2010). Social norms, social networks, and HIV risk behavior among injection drug users. *AIDS and Behavior*, 14(5), 1159-1168.
- Latkin, C., Mandell, W., Oziemkowska, M., Celentano, D., Vlahov, D., Ensminger, M., & Knowlton, A. (1995). Using social network analysis to study patterns of drug use among urban drug users at high risk for HIV/AIDS. *Drug and alcohol dependence*, 38(1), 1-9.
- Latkin, C., Sherman, S., & Knowlton, A. (2003). HIV prevention among drug users: outcome of a network-oriented peer outreach intervention. *Health Psychology*, 22(4), 332.

- Lavanchy, D. (2011). Evolving epidemiology of hepatitis C virus. *Clinical Microbiology and Infection*, 17(2), 107-115.
- Lazuardi, E., Worth, H., Saktiawati, A., Spooner, C., Padmawati, R., & Subronto, Y. (2012). Boyfriends and injecting: the role of intimate male partners in the life of women who inject drugs in Central Java. *Culture, Health & Sexuality*, 14(5), 491-503.
- Le, T. (1997). Peer education on drugs and alcohol project (PEDAP) (Vol. (Unpublished Report)). Cabramatta, NSW.: Cabramatta Community Centre.
- Legal and Discrimination Working Party of MACBBVS. (2014). A series of 7 papers on the impacts of discrimination and criminalisation on public health approaches to blood borne viruses and sexually transmissible infections. Prepared for the Commonwealth Ministerial Advisory Committee on BBV and STIs (MACBBVS). Canberra: MACBBVS.
- Lenton, S., Bevan, J., & Lamond, T. (2006). Threat or opportunity? Secondary exchange in a setting with widespread availability of needles. *Substance Use & Misuse*, 41(6-7), 845-864.
- Leutscher, P., Lagging, M., Buhl, M., Norkrans, G., Langeland, N., Mørch, K., . . . Bech, P. (2010). Evaluation of depression as a risk factor for treatment failure in chronic hepatitis C. *Hepatology*, 52(2), 430-435.
- Levine, H. (2003). Global drug prohibition: its uses and crises. *International Journal of Drug Policy*, 14(2), 145-153.
- Lincoln, Y., & Guba, E. (1985). *Naturalistic inquiry* (Vol. 75): SAGE Publications, Incorporated.
- Lindsay, J., Smith, A., & Rosenthal, D. (1999). Uncertain knowledge: a national survey of high school students' knowledge and beliefs about hepatitis C. *Australian and New Zealand Journal of Public Health*, 23(2), 135-139.
- Lines, R., & Elliott, R. (2007). Injecting drugs into human rights advocacy. *International Journal of Drug Policy*, 18, 453-457.
- Link, B., & Phelan, J. (2006). Stigma and its public health implications. *Lancet*, 367(9509), 528-528.
- Lorvick, J., Bluthenthal, R., Scott, A., Gilbert, M., Riehman, K., Anderson, R., . . . Kral, A. (2006). Secondary Syringe Exchange Among Users of 23 California Syringe Exchange Programs. *Substance Use & Misuse*, 41(6-7), 865-882.
- Lorvick, J., Bluthenthal, R. N., Scott, A., Lou Gilbert, M., Riehman, K. S., Anderson, R. L., . . . Kral, A. H. (2006). Secondary syringe exchange among users of 23 California syringe exchange programs. *Substance Use & Misuse*, 41(6-7), 865-882.
- Louie, R., Krouskos, D., Gonzalez, M., & Crofts, N. (1998). Vietnamese-speaking injecting drug users in Melbourne: the need for harm reduction programs. *Australian and New Zealand Journal of Public Health*, 22(4), 481-484. doi: 10.1111/j.1467-842X.1998.tb01418.x
- Lovell, A. (2002). Risking risk: the influence of types of capital and social networks on the injection practices of drug users. *Social Science & Medicine*, 55(5), 803-821.

- Loxley, W., Bolleter, A., & Carruthers, S. (2001). *Talking about testing: opportunities for prevention in blood borne virus testing and vaccination with injectors*: Curtin University of Technology. National Drug Research Institute Perth, Australia.
- Maasoumy, B., & Wedemeyer, H. (2012). Natural history of acute and chronic hepatitis C. *Best Practice & Research Clinical Gastroenterology*, 26(4), 401-412.
- MacDonald, M., Crofts, N., & Kaldor, J. (1996). Transmission of hepatitis C virus: rates, routes, and cofactors. *Epidemiologic Reviews*, 18(2), 137-148.
- Mackiewicz, V., Dussaix, E., Le Petitcorps, M., -F., & Roque-Afonso, A. (2004). Detection of hepatitis A virus RNA in saliva. *Journal of clinical microbiology*, 42(9), 4329-4331.
- MacLean, S., Bruun, A., & Mallett, S. (2013). 'I've had a pretty tough life but that's not why I do this': narratives of autonomy and control among alcohol and drug service-engaged early teenagers. *Journal of Youth Studies*, 16(2), 206-221.
- Madden, A., & Cavalieri, W. (2007). Hepatitis C prevention and true harm reduction. *Int J Drug Policy*, 18(5), 335-337.
- Madden, A., & Wodak, A. (2014). Australia's Response to HIV Among People Who Inject Drugs. *AIDS Education and Prevention*, 26(3), 234-244.
- Maher, L., Chant, K., Jalaludin, B., & Sargent, P. (2004). Risk behaviours and antibody hepatitis B and C prevalence among injecting drug users in South Western Sydney, Australia. *J Gastroenterol. Hepatol* 19, 1114-1120.
- Maher, L., & Dixon, D. (2001). The cost of crackdowns: Policing Cabramatta's heroin market. *Current Issues in Criminal Justice*, 13(1), 5-21.
- Maher, L., Dixon, D., Swift, W., & Nguyen, T. (1997). Anh hai: Young Asian background people's perceptions and experiences of policing. UNSW: Faculty of Law.
- Maher, L., & Hudson, S. (2007). Women in the drug economy: A metasynthesis of the qualitative literature. *Journal of Drug Issues*, 37(4), 805-826.
- Maher, L., Jalaludin, B., Chant, K., Jayasuriya, R., Sladden, T., Kaldor, J., & Sargent, P. (2006). Incidence and risk factors for hepatitis C seroconversion in injecting drug users in Australia. *Addiction*, 101(10), 1499-1508.
- Maher, L., Li, J., Jalaludin, B., Chant, K., & Kaldor, J. (2007). High hepatitis C incidence in new injecting drug users: a policy failure? *Australian and New Zealand journal of public health*, 31(1), 30-35.
- Maher, L., Sargent, P., Higgs, P., Crofts, N., Kelsall, J., & Le, T. (2001). Risk behaviors of young Indo-Chinese injecting drug users in Sydney and Melbourne. *Australian and New Zealand Journal of Public Health*, 25, 5-21.
- Mandell, W., Kim, J., Latkin, C., & Suh, T. (1999). Depressive symptoms, drug network, and their synergistic effect on needle-sharing behavior among street injection drug users. *The American journal of drug and alcohol abuse*, 25(1), 117-127.

- Manns, M., Wedemeyer, H., & Cornberg, M. (2006). Treating viral hepatitis C: efficacy, side effects, and complications. *Gut*, 55(9), 1350-1359.
- Marcellin, P., Asselah, T., & Boyer, N. (2006). Fibrosis and disease progression in hepatitis C. *Hepatology*, 36(S1), S47-S56.
- Marciniak, C. (2000). Steel City. <http://dl.nfsa.gov.au/module/442/> The National Film & Sound Archive.
- Marmot, M. (2007). Achieving health equity: from root causes to fair outcomes. *The Lancet*, 370(9593), 1153-1163.
- Marshall, C., & Rossman, G. (2010). *Designing qualitative research*. CA: Sage.
- Martin, J. (1991). *Memorandums: Escape from Botany Bay, 1791 : being 'Memorandums' (fl.1786 - 1792)*. Canberra: Mulini Press.
- Mateu-Gelabert, P., Sandoval, M., Meylaks, P., Wendel, T., & Friedman, S. (2010). Strategies to avoid opiate withdrawal: implications for HCV and HIV risks. *International Journal of Drug Policy*, 21(3), 179-185.
- Mateu-Gelabert, P., Treloar, C., Calatayud, V., Sandoval, M., Zurián, J., Maher, L., . . . Friedman, S. (2007). How can hepatitis C be prevented in the long term? *International Journal of Drug Policy*, 18(5), 338-340.
- Mathers, B., Degenhardt, L., Ali, H., Wiessing, L., Hickman, M., Mattick, R., . . . Strathdee, S. (2010). HIV prevention, treatment, and care services for people who inject drugs: a systematic review of global, regional, and national coverage. *The Lancet*, 375(9719), 1014-1028.
- Matthews, G., & Dore, G. (2008). HIV and hepatitis C coinfection. *Journal of gastroenterology and hepatology*, 23(7pt1), 1000-1008.
- Mayock, P. (2002). Drug pathways, transitions and decisions: The experiences of young people in an inner-city Dublin community. *Contemp. Drug Probs.*, 29, 117-156.
- Mayock, P. (2005). 'Scripting'risk: Young people and the construction of drug journeys. *Drugs: Education, Prevention, and Policy*, 12(5), 349-368.
- McCaw, R., Moaven, L., Locarnini, S., & Bowden, D. (2003). Hepatitis C virus genotypes in Australia. *Journal of Viral Hepatitis*, 4(5), 351-357.
- McCaw, R., Moaven, L., Locarnini, S. A., & Bowden, D. S. (1997). Hepatitis C virus genotypes in Australia. *Journal of Viral Hepatitis*, 4(5), 351-357.
- McDonald, D. (2011). Australian governments' spending on preventing and responding to drug abuse should target the main sources of drug-related harm and the most cost-effective interventions. *Drug and Alcohol Review*, 30(1), 96-100.
- McMahon, J. (Writer) & A. B. C. N. 1233 (Director). (2012). Local heroin addicts wait years for treatment, *Hooked on Heroin Series*. <http://www.abc.net.au/local/stories/2012/05/22/3508442.htm>.

- McNeil, R., & Small, W. (2014). 'Safer environment interventions': A qualitative synthesis of the experiences and perceptions of people who inject drugs. *Social Science & Medicine*, 106, 151-158.
- McNeil, R., & Small, W. (2014). 'Safer environment interventions': A qualitative synthesis of the experiences and perceptions of people who inject drugs. *Social Science & Medicine*, 106(0), 151-158.
- Mead, G. (1967). *Mind, self and society*, 1934. *Chicago: U of Chicago P.*
- Memon, M., & Memon, M. (2002). Hepatitis C: an epidemiological review. *Journal of Viral Hepatitis*, 9(2), 84-100.
- Merkinaite, S., Grund, J.-P., & Frimpong, A. (2010). Young people and drugs: Next generation of harm reduction. *International Journal of Drug Policy*, 21(2), 112-114.
- Micallef, J., Kaldor, J., & Dore, G. (2005). Spontaneous viral clearance following acute hepatitis C infection: a systematic review of longitudinal studies. *Journal of Viral Hepatitis*, 13(1), 34-41.
- Miller, C., Johnston, C., Spittal, P., Li, K., LaLiberté, N., Montaner, J., & Schechter, M. (2002). Opportunities for prevention: hepatitis C prevalence and incidence in a cohort of young injection drug users. *Hepatology*, 36(3), 737-742.
- Miller, E., McNally, S., Wallace, J., & Schlichthorst, M. (2012). The ongoing impacts of hepatitis c: A systematic narrative review of the literature. *BMC Public Health*, 12(1), 672.
- Miller, M., & Neaigus, A. (2001). Networks, resources and risk among women who use drugs. *Social Science and Medicine*, 52, 967-978.
- Mitsui, T., Iwano, K., Masuko, K., Yamazaki, C., Okamoto, H., Tsuda, F., . . . Mishiro, S. (1992). Hepatitis C virus infection in medical personnel after needlestick accident. *Hepatology*, 16(5), 1109-1114.
- Moore, D. (2004). Governing street-based injecting drug users: a critique of heroin overdose prevention in Australia. *Social Science & Medicine*, 59(7), 1547-1557.
- Moore, D., & Dietze, P. (2005). Enabling environments and the reduction of drug-related harm: re-framing Australian policy and practice. *Drug and Alcohol Review*, 24(3), 275-284.
- Moore, D., & Fraser, S. (2006). Putting at risk what we know: Reflecting on the drug-using subject in harm reduction and its political implications. *Social Science & Medicine*, 62(12), 3035-3047.
- Morse, J., Barrett, M., Mayan, M., Olson, K., & Spiers, J. (2008). Verification strategies for establishing reliability and validity in qualitative research. *International journal of qualitative methods*, 1(2), 13-22.
- Murphy, S., Kelley, M., & Lune, H. (2004). The health benefits of secondary syringe exchange. *Journal of Drug Issues*, 34(2), 245-268.
- Nadelman, E., McNeely, J., & Drucker, E. (1977). International Perspectives In J. Lowinson, P. Ruiz, R. Millman & J. Langrod (Eds.), *Substance abuse: a comprehensive textbook* (3rd ed., pp. 22-39). Baltimore: Lippincott Williams & Watkins.

- Nathani, J., Iversen, J., Shying, K., Byrne, J., & Maher, L. (2010). Qualitative accounts of needle and syringe cleaning techniques among people who inject drugs in Sydney, Australia. *Drug and Alcohol Review*, 29(4), 413-419.
- National Centre in HIV Epidemiology and Clinical Research. (2009). Return on investment 2: Evaluating the cost-effectiveness of needle and syringe programs in Australia: Australian Government Department of Health and Aging.
- National Centre in HIV Epidemiology and Clinical Research. (2010). 1995-2010 Australian NSP Survey - National Data Report. Sydney: National Centre in HIV Epidemiology and Clinical Research, University of New South Wales.
- Neaigus, A., Friedman, S., Curtis, R., Des Jarlais, D., Terry Furst, R., Jose, B., . . . Ward, T. (1994). The relevance of drug injectors' social and risk networks for understanding and preventing HIV infection. *Social Science & Medicine*, 38(1), 67-78.
- Neaigus, A., Friedman, S., Goldstein, M., Ildefonso, G., Curtis, R., & Jose, B. (1995). Using dyadic data for a network analysis of HIV infection and risk behaviors among injecting drug users. *NIDA research monograph*, 151, 20-37.
- Neaigus, A., Friedman, S., Jose, B., Goldstein, M., Curtis, R., Ildefonso, G., & Des Jarlais, D. (1996). High-risk personal networks and syringe sharing as risk factors for HIV infection among new drug injectors. *JAIDS Journal of Acquired Immune Deficiency Syndromes*, 11(5), 499-509.
- Neaigus, A., Friedman, S., Kottiri, B., & Des Jarlais, D. (2001). HIV risk networks and HIV transmission among injecting drug users. *Evaluation and Program Planning*, 24(2), 221-226.
- Negro, F., & Clement, S. (2009). Impact of obesity, steatosis and insulin resistance on progression and response to therapy of hepatitis C. *Journal of Viral Hepatitis*, 16(10), 681-688.
- Newland, J., & Treloar, C. (2013). Peer education for people who inject drugs in New South Wales: Advantages, unanticipated benefits and challenges. *Drugs: education, prevention and policy*, 20(4), 1-8.
- Newman, C., et al. (2007). 'Everything is okay': The influence of neoliberal discourse on the reported experiences of Aboriginal people in Western Australia who are HIV-positive. *Culture, health & sexuality* 9(6): 571-584.
- Noy, C. (2008). Sampling Knowledge: The Hermeneutics of Snowball Sampling in Qualitative Research. *International Journal of Social Research Methodology*, 11(4), 327-344.
- NSW Department of Health. (2013a). Needle and syringe program policy and guidelines for NSW. North Sydney: NSW Department of Health.
- NSW Department of Health. (2013b). NSW Needle and Syringe Program Guidelines 2013. North Sydney: NSW Department of Health.
- Drug Misuse and Trafficking Act 1985 No 226 (1985).
- NSW Users & AIDS Association. (2009). Deregulation of Needle and Syringe Provision to Improve Distribution and Access to Sterile Injecting Equipment in New South Wales. Sydney: New South Wales Users & AIDS Association.

- O'Brien, S., Day, C., Black, E., & Dolan, K. (2008). Injecting drug users' understanding of hepatitis C. *Addictive Behaviors*, 33(12), 1602-1605.
- Ortiz, V., Berenguer, M., Rayón, J., Carrasco, D., & Berenguer, J. (2002). Contribution of obesity to hepatitis C-related fibrosis progression. *The American journal of gastroenterology*, 97(9), 2408-2414.
- Ostapowicz, G., Watson, K., Locarnini, S., & Desmond, P. (2003). Role of alcohol in the progression of liver disease caused by hepatitis C virus infection. *Hepatology*, 27(6), 1730-1735.
- Owen, G. (2008). An 'elephant in the room'? Stigma and hepatitis C transmission among HIV-positive 'serosorting' gay men. *Culture, Health & Sexuality*, 10(6), 601-610.
- Owen, G. (2013). The Hierarchical Experience of Stigma in HIV/Hepatitis C Co-infected Gay Men *Stigma, Discrimination and Living with HIV/AIDS* (pp. 309-322): Springer.
- Pahl, R., & Spencer, L. (2004). Personal communities: not simply families of 'fate' or 'choice'. *Current Sociology*, 52(2), 199-221.
- Paintsil, E., He, H., Peters, C., Lindenbach, B., & Heimer, R. (2010). Survival of hepatitis C virus in syringes: implication for transmission among injection drug users. *Journal of Infectious Diseases*, 202(7), 984-990.
- Palmateer, N., Anderson, N., Wadd, S., Hutchinson, S., Taylor, A., & Goldberg, D. (2008). Exploring associations between perceived HCV status and injecting risk behaviors among recent initiates to injecting drug use in Glasgow. *Substance use & misuse*, 43(3-4), 375-388.
- Palmateer, N., Kimber, J., Hickman, M., Hutchinson, S., Rhodes, T., & Goldberg, D. (2010). Evidence for the effectiveness of sterile injecting equipment provision in preventing hepatitis C and human immunodeficiency virus transmission among injecting drug users: a review of reviews. *Addiction*, 105(5), 844-859.
- Paquette, D., Bryant, J., & De Wit, J. (2011). Use of respondent-driven sampling to enhance understanding of injecting networks: A study of people who inject drugs in Sydney, Australia. *International Journal of Drug Policy*, 22(4), 267-273.
- Paquette, D., Bryant, J., & De Wit, J. (2012). Comparison of participants from respondent-driven sampling and service-based sampling studies of people who inject drugs. *Drugs: Education, Prevention, and Policy*, 19(4), 329-338. doi: doi:10.3109/09687637.2011.631198
- Parker, R., & Aggleton, P. (2003). HIV and AIDS-related stigma and discrimination: a conceptual framework and implications for action. *Social Science & Medicine*, 57(1), 13-24.
- Paterson, B., Backmund, M., Hirsch, G., & Yim, C. (2007). The depiction of stigmatization in research about hepatitis C. *International Journal of Drug Policy*, 18(5), 364-373.
- Patrick, D., Tyndall, M., Cornelisse, P., Li, K., & et al. (2001). Incidence of hepatitis C virus infection among injection drug users during an outbreak of HIV infection. *Canadian Medical Association. Journal*, 165(7), 889-895.
- Patton, M. (2002). *Qualitative evaluation and research methods* (3rd ed.). London: Sage Publications.

- Peltzer, K., & Ramlagan, S. (2011). Perceived stigma among patients receiving antiretroviral therapy: A prospective study in KwaZulu-Natal, South Africa. *AIDS Care - Psychological and Socio-Medical Aspects of AIDS/HIV*, 23(1), 60-68.
- Perz, J., Armstrong, G., Farrington, L., Hutin, Y., & Bell, B. (2006). The contributions of hepatitis B virus and hepatitis C virus infections to cirrhosis and primary liver cancer worldwide. *Journal of Hepatology*, 45(4), 529-538.
- Pouget, E., Hagan, H., & Des Jarlais, D. (2012). Meta-analysis of hepatitis C seroconversion in relation to shared syringes and drug preparation equipment. *Addiction*, 107(6), 1057-1065.
- Power, R., Jones, S., Kearns, G., & Ward, J. (1995). Drug user networks, coping strategies, and HIV prevention in the community. *Journal of Drug Issues*.
- Prawat, R. (1996). Constructivisms, modern and postmodern. *Educational Psychologist*, 31(3-4), 215-225.
- Purcell, R., Alter, H., & Dienstag, J. (1976). Non-A, non-B hepatitis. *The Yale journal of biology and medicine*, 49(3), 243-250.
- Rachlis, B., Brouwer, K., Mills, E., Hayes, M., Kerr, T., & Hogg, R. (2007). Migration and transmission of blood-borne infections among injection drug users: understanding the epidemiologic bridge. *Drug and Alcohol Dependence*, 90(2), 107-119.
- Ramos, R., Ferreira-Pinto, J., Brouwer, K., Ramos, M., Lozada, R., Firestone-Cruz, M., & Strathdee, S. (2009). A tale of two cities: social and environmental influences shaping risk factors and protective behaviors in two Mexico-US border cities. *Health & Place*, 15(4), 999-1005.
- Randolph, B., & Holloway, D. (2005). Social disadvantage, tenure and location: an analysis of Sydney and Melbourne. *Urban Policy and Research*, 23(2), 173-201.
- Razali, K., Thein, H., Bell, J., Cooper-Stanbury, M., Dolan, K., Dore, G., . . . Li, J. (2007). Modelling the hepatitis C virus epidemic in Australia. *Drug and Alcohol Dependence*, 91(2), 228-235.
- Razzaghi, E., Movaghar, A., Green, T., & Khoshnood, K. (2006). Profiles of risk: a qualitative study of injecting drug users in Tehran, Iran. *Harm Reduction Journal*, 3(1), 12.
- Rhodes, T. (1993). Time for community change: what has outreach to offer? *Addiction*, 88(10), 1317-1320.
- Rhodes, T. (2002). The 'risk environment': a framework for understanding and reducing drug-related harm. *International Journal of Drug Policy*, 13(2), 85-94.
- Rhodes, T. (2009). Risk environments and drug harms: A social science for harm reduction approach. *International Journal of Drug Policy*, 20(3), 193-201.
- Rhodes, T., & Cusick, L. (2000). Love and intimacy in relationship risk management: HIV positive people and their sexual partners. *Sociology of Health & Illness*, 22(1), 1-26.
- Rhodes, T., Davis, M., & Judd, A. (2004). Hepatitis C and its risk management among drug injectors in London: renewing harm reduction in the context of uncertainty. *Addiction*, 99(5), 621-633.

- Rhodes, T., Harris, M., & Martin, A. (2013). Negotiating access to medical treatment and the making of patient citizenship: the case of hepatitis C treatment. *Sociology of Health & Illness*, 35(7), 1023-1044.
- Rhodes, T., Kimber, J., Small, W., Fitzgerald, J., Kerr, T., Hickman, M., & Holloway, G. (2006). Public injecting and the need for 'safer environment interventions' in the reduction of drug-related harm. *Addiction*, 101(10), 1384-1393.
- Rhodes, T., Kuneski, E., & Bernays, S. (2008). Hygiene and uncertainty in qualitative accounts of hepatitis C transmission among drug injectors in Serbia. *Social Science & Medicine*, 66(6), 1437-1447.
- Rhodes, T., Mikhailova, L., Sarang, A., Lowndes, C., Rylkov, A., Khutorskoy, M., & Renton, A. (2003). Situational factors influencing drug injecting, risk reduction and syringe exchange in Togliatti City, Russian Federation: a qualitative study of micro risk environment. *Social Science & Medicine*, 57(1), 39-54.
- Rhodes, T., & Quirk, A. (1998). Drug users' sexual relationships and the social organisation of risk: the sexual relationship as a site of risk management. *Social Science & Medicine*, 46(2), 157-169.
- Rhodes, T., & Simic, M. (2005). Transition and the HIV risk environment. *BMJ*, 331(7510), 220-223.
- Rhodes, T., Singer, M., Bourgois, P., Friedman, S., & Strathdee, S. (2005). The social structural production of HIV risk among injecting drug users. *Social Science & Medicine*, 61, 1026-1044.
- Rhodes, T., Stoneman, A., Hope, V., Hunt, N., Martin, A., & Judd, A. (2006). Groin injecting in the context of crack cocaine and homelessness: From 'risk boundary' to 'acceptable risk'? *International Journal of Drug Policy*, 17(3), 164-170.
- Rhodes, T., & Treloar, C. (2008). The social production of hepatitis C risk among injecting drug users: a qualitative synthesis. *Addiction*, 103(10), 1593-1603.
- Rhodes, T., Wagner, K., Strathdee, S., Shannon, K., Davidson, P., & Bourgois, P. (2012). Structural violence and structural vulnerability within the risk environment: theoretical and methodological perspectives for a social epidemiology of HIV risk among injection drug users and sex workers *Rethinking Social Epidemiology* (pp. 205-230): Springer.
- Rhodes, T., Wagner, K., Strathdee, S. A., Shannon, K., Davidson, P., & Bourgois, P. (2012). Structural violence and structural vulnerability within the risk environment: theoretical and methodological perspectives for a social epidemiology of HIV risk among injection drug users and sex workers *Rethinking Social Epidemiology* (pp. 205-230): Springer.
- Rhodes, T., Watts, L., Davies, S., Martin, A., Smith, J., Clark, D., . . . Lyons, M. (2007). Risk, shame and the public injector: A qualitative study of drug injecting in South Wales. *Social Science & Medicine*, 65(3), 572-585.
- Richardson, L., Wood, E., Li, K., & Kerr, T. (2010). Factors associated with employment among a cohort of injection drug users. *Drug and Alcohol Review*, 29(3), 293-300.
- Riley, D., & O'Hare, P. (2000). Harm Reduction: History, Definition and Practice. In J. Inciardi & L. Harrison (Eds.), *Harm Reduction: National and International Perspectives* (pp. 1-26): Thousand Oaks: Sage.

- Ritter, A., & Cameron, J. (2006). A review of the efficacy and effectiveness of harm reduction strategies for alcohol, tobacco and illicit drugs. *Drug and Alcohol Review*, 25(6), 611-624.
- Ritter, A., McLeod, R., & Shanahan, M. (2013a). Government Drug Policy Expenditure in Australia 2009/10. Sydney: Drug Modelling Program, National Drug & Alcohol Research Centre, UNSW.
- Ritter, A., McLeod, R., & Shanahan, M. (2013b). Monography No. 24: Government drug policy expenditure in Australia - 2009/10 *DPMP Monograph Series*. Sydney: National Drug and Alcohol Research Centre: University of New South Wales.
- Roberts, E., & Yeung, L. (2006). Maternal-infant transmission of hepatitis C virus infection. *Hepatology*, 36(S1), S106-S113.
- Robson, C. (1993). Real world research: A resource for social scientists and practitioners-researchers. *Blackwell Publishers Ltd., Oxford*.
- Rockstroh, J., & Spengler, U. (2004). HIV and hepatitis C virus co-infection. *The Lancet Infectious Diseases*, 4(7), 437-444.
- Romano, C., de Carvalho-Mello, I., Jamal, L., de Melo, F., Iamarino, A., Motoki, M., . . . de Andrade Zantotto, P. (2010). Social networks shape the transmission dynamics of hepatitis C virus. *PloS one*, 5(6), e11170.
- Roy, É., Nonn, É., Haley, N., & Cox, J. (2007). Hepatitis C meanings and preventive strategies among street-involved young injection drug users in Montréal. *International Journal of Drug Policy*, 18(5), 397-405.
- Sacks-Davis, R., Daraganova, G., Aitken, C., Higgs, P., Tracy, L., Bowden, S., . . . Robins, G. (2012). Hepatitis C Virus Phylogenetic Clustering Is Associated with the Social-Injecting Network in a Cohort of People Who Inject Drugs. *PloS one*, 7(10), e47335.
- Sacks-Davis, R., Horyniak, D., Grebely, J., & Hellard, M. (2012). Behavioural interventions for preventing hepatitis C infection in people who inject drugs: a global systematic review. *International Journal of Drug Policy*, 23(3), 176-184.
- Salganik, M., & Heckathorn, D. (2004). Sampling and estimation in hidden populations using respondent-driven sampling. *Sociological methodology*, 34(1), 193-240.
- Sarang, A., Rhodes, T., Sheon, N., & Page, K. (2010). Policing drug users in Russia: risk, fear, and structural violence. *Substance Use & Misuse*, 45(6), 813-864.
- Sarkar, S., & Lim, J. (2014). Advances in interferon-free hepatitis C therapy: 2014 and beyond. *Hepatology*, 59(4), 1641-1644.
- Sayce, L. (1998). Stigma, discrimination and social exclusion: What's in a word? *Journal of Mental Health*, 7(4), 331-343.
- Scheft, H., & Fontenette, D. (2005). Psychiatric barriers to readiness for treatment for hepatitis C Virus (HCV) infection among injection drug users: clinical experience of an addiction psychiatrist in the HIV-HCV coinfection clinic of a public health hospital. *Clinical Infectious Diseases*, 40(Supplement 5), S292-S296.

- Seear, K., Gray, R., Fraser, S., Treloar, C., Bryant, J., & Brener, L. (2012). Rethinking safety and fidelity: The role of love and intimacy in hepatitis C transmission and prevention. *Health Sociology Review, 21*(3), 272-286.
- Seeff, L. (2002). Natural history of chronic hepatitis C. *Hepatology, 36*(S1), S35-S46.
- Serovich, J. (2001). A test of two HIV disclosure theories. *AIDS education and prevention: official publication of the International Society for AIDS Education, 13*(4), 355-364.
- Sgorbini, M., O'Brien, L., & Jackson, D. (2009). Living with hepatitis C and treatment: the personal experiences of patients. *Journal of clinical nursing, 18*(16), 2282-2291.
- Shahbazi, M., Farnia, M., Keramati, M., & Alasvand, R. (2010). Advocacy and piloting the first needle and syringe exchange program in Iranian prisons. *Retrovirology, 7*(Suppl 1), P81.
- Shannon, K., Kerr, T., Allinott, S., Chettiar, J., Shoveller, J., & Tyndall, M. (2008). Social and structural violence and power relations in mitigating HIV risk of drug-using women in survival sex work. *Social Science & Medicine, 66*(4), 911-921.
- Shelley, G., Bernard, H., Killworth, P., Johnsen, E., & McCarty, C. (1995). Who knows your HIV status? What HIV+ patients and their network members know about each other. *Social Networks, 17*(3), 189-217.
- Shepard, C., Finelli, L., & Alter, M. (2005). Global epidemiology of hepatitis C virus infection. *The Lancet Infectious Diseases, 5*(9), 558-567.
- Sherman, S., & Latkin, C. (2002). Drug users' involvement in the drug economy: Implications for harm reduction and HIV prevention programs. *Journal of Urban Health, 79*(2), 266-277. doi: 10.1093/jurban/79.2.266
- Sherman, S., Latkin, C., & Gielen, A. (2001). Social factors related to syringe sharing among injecting partners: a focus on gender. *Substance Use & Misuse, 36*(14), 2113-2136.
- Simmonds, L., & Coomber, R. (2009). Injecting drug users: A stigmatised and stigmatising population. *International Journal of Drug Policy, 20*(2), 121-130.
- Small, W., Rhodes, T., Wood, E., & Kerr, T. (2007). Public injection settings in Vancouver: Physical environment, social context and risk. *International Journal of Drug Policy, 18*(1), 27-36.
- Smith, B., Jewett, A., Burt, R., Zibbell, J., Yartel, A., & DiNenno, E. (2013). "To Share or Not to Share?" Serosorting by Hepatitis C Status in the Sharing of Drug Injection Equipment Among NHBS-IDU2 Participants. *Journal of Infectious Diseases, 208*(12), 1934-1942. doi: 10.1093/infdis/jit520
- Smith, B., Bauman, A., Chen, J., Loveday, S., Costello, M., Mackie, B., & Dore, G. (2006). Hepatitis C in Australia: impact of a mass media campaign. *American journal of preventive medicine, 31*(6), 492-498.
- Smith, C. (2010). Socio-spatial stigmatization and the contested space of addiction treatment: remapping strategies of opposition to the disorder of drugs. *Social Science & Medicine, 70*(6), 859-866.

- Smith, R., Rossetto, K., & Peterson, B. (2008). A meta-analysis of disclosure of one's HIV-positive status, stigma and social support. *AIDS care*, 20(10), 1266-1275.
- Snead, J., Downing, M., Lorvick, J., Garcia, B., Thawley, R., Kegeles, S., & Edlin, B. (2003). Secondary syringe exchange among injection drug users. *Journal of urban health : bulletin of the New York Academy of Medicine*, 80(2), 330-348.
- Snead, J., Downing, M., Lorvick, J., Garcia, B., Thawley, R., Kegeles, S., & Edlin, B. R. (2003). Secondary syringe exchange among injection drug users. *Journal of Urban Health*, 80(2), 330-348.
- Southgate, E., & Hopwood, M. (2001). The role of folk pharmacology and lay experts in harm reduction: Sydney gay drug using networks. *International Journal of Drug Policy*, 12(4), 321-335.
- Stein, J., & Nyamathi, A. (2004). Correlates of hepatitis C virus infection in homeless men: a latent variable approach. *Drug and Alcohol Dependence*, 75(1), 89-95.
- Stopka, T. (2006). Editor's introduction to this special issue on syringe access and secondary syringe exchange: international perspectives and future directions. *Substance Use & Misuse*, 41(6-7), 771-776.
- Strader, D., Wright, T., Thomas, D., & Seeff, L., . (2004). Diagnosis, management, and treatment of hepatitis C. *Hepatology*, 39(4), 1147-1171.
- Strathdee, S., Hallett, T., Bobrova, N., Rhodes, T., Booth, R., Abdool, R., & Hankins, C. (2010). HIV and risk environment for injecting drug users: the past, present, and future. *The Lancet*, 376(9737), 268-284.
- Sutton, R., & Treloar, C. (2007). Chronic illness experiences, clinical markers and living with hepatitis C. *Journal of Health Psychology*, 12(2), 330-340.
- Swift, W., Maher, L., & Sunjic, S. (1999). Transitions between routes of heroin administration: a study of Caucasian and Indochinese heroin users in south-western Sydney, Australia. *Addiction*, 94(1), 71-82.
- Tangney, J., & Dearing, R. (2002). *Shame and guilt*. New York: Guilford Press.
- Taylor, D., & Jelsma, M. (2012). The UN Drug Control Conventions: The Limits of Latitude. *IDPC Series on Legislative Reform of Drug Policies*(18).
- Tedeschi, V., & Seeff, L. (1995). Diagnostic Tests for Hepatitis C: Where Are We Now? *Annals of Internal Medicine*, 123(5), 383-385.
- Tempalski, B., & McQuie, H. (2009). Druggscapes and the role of place and space in injection drug use-related HIV risk environments. *International Journal of Drug Policy*, 20(1), 4-13.
- Terrault, N. (2006). Sexual activity as a risk factor for hepatitis C. *Hepatology*, 36(S1), S99-S105.
- The Boston Consulting Group. (2012). The Economic Impact of Hepatitis C in Australia. Sydney: The Boston Consulting Group.

- The Kirby Institute. (2011). HIV, viral hepatitis and sexually transmissible infections in Australia Annual Surveillance Report 2011. The University of New South Wales, Sydney, NSW: The Kirby Institute.
- The Kirby Institute. (2012). HIV, viral hepatitis and sexually transmissible infections in Australia Annual Surveillance Report 2012. Sydney, NSW: The Kirby Institute, The University of New South Wales.
- Thein, H.-H., Yi, Q., Dore, G., & u. D. (2008). Estimation of stage-specific fibrosis progression rates in chronic hepatitis C virus infection: A meta-analysis and meta-regression. *Hepatology*, 48(2), 418-431.
- Thorpe, L., Ouellet, L., Hershow, R., Bailey, S., Williams, I., Williamson, J., . . . Garfein, R. (2002). Risk of hepatitis C virus infection among young adult injection drug users who share injection equipment. *American journal of epidemiology*, 155(7), 645-653.
- Topp, L., Day, C., & Degenhardt, L. (2003). Changes in patterns of drug injection concurrent with a sustained reduction in the availability of heroin in Australia. *Drug and Alcohol Dependence*, 70(3), 275-286.
- Totaro, P., & Pollard, R. (2003, 16 July 2003). Anger as police surveillance film forces closure of Cabramatta drug clinic. , *Sydney Morning Herald*. Retrieved from www.smh.com.au/articles/2003/07/15/1058035010401.html
- Treloar, C. (2005). 'You Sort of Switch Off': Exploring Mindlessness in Injecting Drug Users' Accounts of Blood. *Journal of health psychology*, 10(1), 137-145.
- Treloar, C., & Abelson, J. (2005). Information exchange among injecting drug users: a role for an expanded peer education workforce. *International Journal of Drug Policy*, 16(1), 46-53.
- Treloar, C., & Holt, M. (2006). Deficit models and divergent philosophies: Service providers' perspectives on barriers and incentives to drug treatment. *Drugs: Education, Prevention, and Policy*, 13(4), 367-382.
- Treloar, C., & Hopwood, M. (2004). Infection control in the context of hepatitis C disclosure: Implications for education of health professionals. *Education for Health*, 17, 183-191.
- Treloar, C., Hull, P., Bryant, J., Hopwood, M., Grebely, J., & Lavis, Y. (2011). Factors associated with hepatitis C knowledge among a sample of treatment naive people who inject drugs. *Drug and Alcohol Dependence*, 116(1-3), 52-56.
- Treloar, C., Hull, P., Dore, G., & Grebely, J. (2012). Knowledge and barriers associated with assessment and treatment for hepatitis C virus infection among people who inject drugs. 31(7), 918-924.
- Treloar, C., Laybutt, B., Jauncey, M., van Beek, I., Lodge, M., Malpas, G., & Carruthers, S. (2008). Broadening discussions of "safe" in hepatitis C prevention: A close-up of swabbing in an analysis of video recordings of injecting practice. *International Journal of Drug Policy*, 19(1), 59-65.
- Treloar, C., Newland, J., Harris, M., Deacon, R., & Maher, L. (2010). A diagnosis of hepatitis C-insights from a study on patients' experiences. *Australian family physician*, 39(8), 589-592.

- Treloar, C., Rance, J., & Backmund, M. (2013). Understanding Barriers to Hepatitis C Virus Care and Stigmatization From a Social Perspective. *Clinical infectious diseases*, 57(suppl 2), S51-S55. doi: 10.1093/cid/cit263
- Trotter, R. (1999). Friends, relatives and relevant others: conducting ethnographic network studies. In J. Schensul & M. LeCompte (Eds.), *Mapping Social Networks, Spatial Data, and Hidden Populations* (Vol. 4, pp. 1-50). Walnut Creek: Altamira.
- Tsui, J., Vittinghoff, E., Hahn, J., Evans, J., Davidson, P., & Page, K. (2009). Risk behaviors after hepatitis C virus seroconversion in young injection drug users in San Francisco. *Drug and Alcohol Dependence*, 105(1), 160-163.
- Turner, J. (1982). Coal Mining in Newcastle: 1801-1900. *Newcastle History Monographs No.9*. Retrieved from http://www.newcastle.nsw.gov.au/data/assets/pdf_file/0010/115984/Preliminary_pages.pdf
- Tyler, K. (2008). Social network characteristics and risky sexual and drug related behaviors among homeless young adults. *Social Science Research*, 37(2), 673-685.
- Tyndall, M., Bruneau, J., Brogly, S., Spittal, P., O'Shaughnessy, M., & Schechter, M. (2002). Satellite needle distribution among injection drug users: policy and practice in two Canadian cities. *JAIDS Journal of Acquired Immune Deficiency Syndromes*, 31(1), 98-105.
- Unger, J., Kipke, M., De Rosa, C., Hyde, J., Ritt-Olson, A., & Montgomery, S. (2006). Needle-sharing among young IV drug users and their social network members: The influence of the injection partner's characteristics on HIV risk behavior. *Addictive Behaviors*, 31(9), 1607-1618.
- Valente, T., Foreman, R., Junge, B., & Vlahov, D. (1998). Satellite exchange in the Baltimore Needle Exchange Program. *Public Health Reports*, 113(Suppl 1), 90-96.
- van Beek, I. (2000). Approaches to injecting drug use in Kings Cross: a review of the last 10 years. *New South Wales Public Health Bulletin*, 11(4), 54-55.
- Van Beek, I. (2003). The Sydney medically supervised injecting centre: A clinical model. *Journal of Drug Issues*, 33(3), 625-638.
- van Beek, I., Kimber, J., Dakin, A., & Gilmour, S. (2004). The Sydney Medically Supervised Injecting Centre: reducing harm associated with heroin overdose. *Critical Public Health*, 14(4), 391-406. doi: 10.1080/09581590400027528
- Videnieks, V. (2003). Heroin deals ends needle program. *The Australian*. July 12 2003.
- Voon, D., & Ryan, J. (2011). Inside Information: Prison Needle and Syringe Protocols. Melbourne: Anex.
- Voytek, C., Sherman, S., & Junge, B. (2003). A matter of convenience: factors influencing secondary syringe exchange in Baltimore, Maryland, USA. *International Journal of Drug Policy*, 14(5), 465-467.
- Wagner, K., Iverson, E., Wong, C., Bloom, J., McNeeley, M., Davidson, P., . . . Lankenau, S. (2013). Personal Social Network Factors Associated with Overdose Prevention Training Participation. *Substance Use & Misuse*, 48(1-2), 21-31.

- Warhaft, G., Black, E., & Sindich, N. (2007). Heroin: Is smack coming back? *Users News*, 52 (Summer 2008). Retrieved from http://www.nuaa.org.au/index.php?option=com_content&view=article&id=129:heroin-is-smack-coming-back&catid=8:issue-no-52-summer-200708&Itemid=5
- Wasserman, S., & Faust, K. (1994). *Social network analysis: Methods and applications* (Vol. 8): Cambridge university press.
- Weeks, M., Clair, S., Borgatti, S., Radda, K., & Schensul, J. (2002). Social Networks of Drug Users in High-Risk Sites: Finding the Connections. *AIDS and Behavior*, 6(2), 193-206.
- Wesley Mission. (2011). More than a bed: Sydney's homeless families speak out. (Vol. Wesley Report): The Wesley Mission.
- Westin, J., Lagging, L., Spak, F., Aires, N., Svensson, E., Lindh, M., . . . Wejstål, R. (2002). Moderate alcohol intake increases fibrosis progression in untreated patients with hepatitis C virus infection. *Journal of Viral Hepatitis*, 9(3), 235-241.
- Wiebel, W. (1990). Identifying and gaining access to hidden populations. *NIDA Res Monogr*, 98, 4-11.
- Wiley, T., McCarthy, M., Breidi, L., McCarthy, M., & Layden, T. (2003). Impact of alcohol on the histological and clinical progression of hepatitis C infection. *Hepatology*, 28(3), 805-809.
- Winter, R., Fraser, S., Booker, N., & Treloar, C. (2011). Technical review of hepatitis C health promotion resources (Vol. Monograph 5/11). Sydney: National Centre in HIV Social Research.
- Wodak, A. (1997). Injecting nation: Achieving control of hepatitis C in Australia. *Drug and Alcohol Review*, 16(3), 275-284.
- Wodak, A. (2001). Drug laws: war on drugs does more harm than good. *BMJ: British Medical Journal*, 323(7317), 866.
- Wodak, A., & Crofts, N. (1996). Once more unto the breach: controlling hepatitis C in injecting drug users. *Addiction*, 91(2), 181-184.
- Wodak, A., & McLeod, L. (2008). The role of harm reduction in controlling HIV among injecting drug users. *AIDS (London, England)*, 22(Suppl 2), S81.
- Wodak, A., Ryan, J., Griffiths, P., van Beek, I., Barratt, M., Lenton, S., . . . Farrell, M. (2012). Policy and Practice in Harm Reduction in Australia. *Harm Reduction in Substance Use and High-Risk Behaviour*, 405.
- Wood, E., Kerr, T., Spittal, P., Small, W., Tyndall, M., O'Shaughnessy, M., & Schechter, M. (2003). An external evaluation of a peer-run "unsanctioned" syringe exchange program. *Journal of Urban Health*, 80(3), 455-464.
- World Health Organisation. (2012a). Guidance on prevention of viral hepatitis B and C among people who inject drugs. Geneva: World Health Organisation.
- World Health Organisation. (2012b). Prevention & Control of Viral Hepatitis Infection: Framework for Global Action. Geneva: World Health Organisation.

- Wozniak, L., Prakash, M., Taylor, M., & Wild, T. (2007). Everybody's got it, but...: Situational and strategic participation in normalized HCV discourse among injection drug users in Edmonton, Canada. *International Journal of Drug Policy*, 18(5), 388-396.
- Yin, R. (2008). *Case study research: Design and methods* (Vol. 5): SAGE Publications, Incorporated.
- Zickmund, S., Bryce, C., Blasiolo, J., Shinkunas, L., LaBrecque, D., & Arnold, R. (2006). Majority of patients with hepatitis C express physical, mental, and social difficulties with antiviral treatment. *European journal of gastroenterology & hepatology*, 18(4), 381-388.

Appendix A Associated conference presentations

Work in progress analyses from this study were presented at a number of national and international conferences:

Newland, J. (2014, February). How hepatitis C was discussed in three social networks of Australian who inject drugs. Paper presented at the 13th Social Research Conference on HIV, Viral hepatitis and Related Diseases, 21 February 2014: UNSW, Sydney.

Newland, J. (2011, April). Secondary syringe exchange: a pre-existing, effective and illegal model of sterile injection equipment distribution in New South Wales, Australia. Poster presented at the International Harm Reduction Associations' 22nd International Conference, (3-7 April, 2011): Beirut, Lebanon.

Newland, J. (2010, November). The interplay of social network and structural influences on hepatitis C harm reduction in New South Wales, Australia. Paper presented at 8th National US National Harm Reduction Conference, 19 November 2011: Austin, Texas, United States.

Newland, J. (2010, November). Secondary syringe exchange: a pre-existing, effective and illegal model of sterile injection equipment distribution in New South Wales, Australia. Paper presented at 8th National US Harm Reduction Conference, 20 November 2011: Austin, Texas, United States.

Newland, J. (2010, September). Peer distribution: a pre-existing, effective and illegal model of sterile injection equipment distribution in New South Wales. Paper presented at the 7th Australasian Viral Hepatitis Conference, 8 September 2010: Melbourne, Australia.

Newland, J. (2010). Peer distribution: A harm reduction practice that is necessary and illegal. Paper presented the NSW Department of Health, Workforce Development Program: Sydney, Australia.

Newland, J. (2010, March) title: Paper presented at the 11th Social Research Conference on HIV, Viral Hepatitis and Related Diseases Social Research Conference, (X March, 2010): Sydney, Australia.

Newland, J. (2010, March) title: Paper presented at the 11th Social Research Conference on HIV, Viral Hepatitis and Related Diseases Social Research Conference, (X March, 2010): Sydney, Australia.

Appendix B Interview Schedule

Individual Demographics

- Gender
- Age
- Post code
- Age at first injection
- Ethnicity
- Hepatitis C status
- Relationship status
- Highest education level
- Main income source
- Incarceration

Drug taking behaviours

- Preferred drug of choice?
- Frequency of injecting?
- Most commonly used place to inject drugs?

Geographic context and service utilisation

- What services are available in your area?
- Which ones do you use?
- How did you hear about them?
- Why do you use them?
- Which ones do you not use? Why?
- Do you have a good relationship with them? Why?
- Do you use any services outside your local area? Which ones? Why?
- What are the coppers like?

Injecting equipment access

- Source of majority of new needles and syringes acquired?
- Main Reason for source of syringes?
- What other equipment do you get/buy? / Source of other equipment?
- Main reason for source of other equipment?
- How many fits would you pick up at a time and how often?
- Do you receive or distribute injecting equipment to others in your network?

Knowledge of hepatitis C

- What is hepatitis C?
- Where did you learn this knowledge?
- Is hepatitis C a risk for you? How and why?
- Do you think hepatitis C is serious?
- Is hepatitis C a priority for you?
- What do you wish you were told about hepatitis C?

Social Network Characteristics (diagrammatically represent in Sociogram)

- How many people do you regularly interact with? (Determining social network size including demographic characteristics such as gender, age, length of time known)
- What are the relationships and roles amongst these members? (network density, structure and core groups)
- Is there much mixing between your network and others? If so, by whom? (determining bridging populations)

Social Network Exchange

- What hepatitis C-related discussions have you had with your social network (content and between whom)?
- What other harm reduction knowledge is being exchanged between people in your network?
- What interest is there in these things?
- Where else do you seek information?
- Why do you seek this information from this source?
- Who do you learn the most from and why?

Social Network power, norms, values and behaviours

- Are there any rules about the buying, making, sharing, and taking of drugs within your network?
- Can you remember a time when you imitated or copied a person/people in your drug using practices? How? Why?
- Can you remember a time when this person communicated and persuaded, you into something to do with your drug using practices? What? Why?
- Can you remember a time when this person coerced (pressured) you into something to do with your drug taking practices? What? Why?

Appendix C Human Research Ethics Clearance (HREC 09022)

THE UNIVERSITY OF
NEW SOUTH WALES



HUMAN RESEARCH ETHICS
COMMITTEE (HREC)

6 March 2009

A/Professor Carla Treloar
National Centre in HIV Social Research
Robert Webster Building

ENTERED ON DATABASE

Dear Professor Treloar,

The situational impacts of informal peer exchange on HCV harm reduction: an exploration into social networks, relationships, gender and culture and the impacts these have on hepatitis C virus (HCV) harm reduction
HREC 09022

Thank you for the email from Ms James Newland to the Ethics Secretariat dated 27 February 2009.

At the Executive Meeting held on 3 March 2009, the Committee provided approval for the above project to proceed. In accordance with the guidelines set out in the National Statement on Ethical Conduct in Research Involving Humans* (NS) and exercising the authority delegated by the Deputy Vice-Chancellor (Research), I give permission for this project to proceed.

Would you please note:-

- approval is valid for five years (from the date of the executive approval i.e. 3 March 2009);
- you will be required to provide annual reports on the study's progress and any adverse events to the HREC, as recommended by the National Statement on Ethical Conduct in Research Involving Humans;
- you are required to immediately report anything which might warrant review of ethical approval of the protocol (NS 2.37), including:
 - (a) serious or unexpected adverse effects on participants;
 - (b) proposed changes in the protocol; and
 - (c) unforeseen events that might affect continued ethical acceptability of the project;
- any modifications to the project must have the prior written approval of the Committee;

.. 2 ..

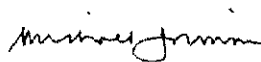
UNSW SYDNEY NSW 2052
A U S T R A L I A
Telephone: +61 (2) 9385 4234
Facsimile: +61 (2) 9385 6648
Email: ethics.sec@unsw.edu.au
Location: Rupert Myers Building
C/o Research Office / Ethics,
Gate 14, Barker Street Kensington
ABN 57 195 873 179

(HREC 09022 cont'd)

.. 2 ..

- the Ethics Secretariat should be notified if serious or unexpected outcomes are experienced by research participants or if there are unforeseen events;
- consent forms are to be retained within the archives of the Centre and made available to the Committee upon request;
- if this approval relates to a clinical trial any serious adverse event arising in the course of the study should be reported promptly using the proforma on the Human Research Ethics website at http://www.gmo.unsw.edu.au/Ethics/HumanEthics/InformationForApplicants/ProformasTemplates/C13_SAE%20Proforma.rtf

Yours sincerely,



Professor Michael Grimm
Presiding Member
HREC

* <http://www.nhmrc.gov.au>

Appendix D HREC (09022) amendment

THE UNIVERSITY OF
NEW SOUTH WALES



HUMAN RESEARCH ETHICS
COMMITTEE (HREC)

20 January 2010

A/Professor Carla Treloar
National Centre in HIV Social Research
Robert Webster Building

Dear Professor Treloar,

The situational impacts of informal peer exchange on HCV harm reduction: an exploration into social networks, relationships, gender and culture and the impacts these have on hepatitis C virus (HCV) harm reduction
HREC 09022

At the executive meeting held on 11 August 2009, the Committee noted and approved the modifications as detailed in your email and attachments to the Ethics Secretariat dated 5 August 2009. The addition of the sites Newcastle and Lismore were approved.

The UNSW HREC period of approval for this project is valid for 5 years from the original approval date, ie. 3 March 2009 to 2 March 2014.

Yours sincerely,

Professor Michael Grimm
Presiding Member
HREC

* <http://www.nhmrc.gov.au>

UNSW SYDNEY NSW 2052
A U S T R A L I A
Telephone: +61 (2) 9385 4234
Facsimile: +61 (2) 9385 6648
Email: ethics.sec@unsw.edu.au
Location: Rupert Myers Building
C/o Research Office / Ethics,
Gate 14, Barker Street Kensington
ABN 57 195 873 179

Appendix E Participant information statement

THE UNIVERSITY OF
NEW SOUTH WALES



Approval No HREC 09022

The Situational Impacts of Informal Peer Exchange on HCV Harm Reduction: An exploration into social networks, relationships, gender and culture and the impacts these have on hepatitis C virus (HCV) harm reduction.

Participant selection and purpose of study

You are invited to participate in a study about the impact of social networks for Hepatitis C (HCV) harm reduction. We hope to learn more about how you and your peers discuss hepatitis C, risks and other biomedical concepts, e.g. vaccines. You were selected as a possible participant in this study because you responded to a research flyer placed at NUAA and you contacted the researcher indicating that you might be interested in participating.

Description of study and risks

If you decide to participate, we will ask you to tell us in detail about your knowledge of hepatitis C, its risks and other biomedical knowledge. We will also ask you about how and what information is exchanged within your social network and how gender, age or network composition affects information exchange. The interview will be held in a suitable location where your confidentiality will be maintained. We will audio-tape the interview and the interview will last for about one hour. We cannot and do not guarantee or promise that you will receive any benefits from this study.

Confidentiality and disclosure of information

Any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission, except as required by law. If you give the researcher your permission by signing this document, we plan to publish the most important results in academic journals, community-based magazines, and policy documents. A number of measures will be put in place to ensure participant confidentiality. Following the interview, all your contact details will be removed from our records.

Following transcription of the interview your real name will be replaced with a pseudonym (or nickname). In addition, all other details you mention that might identify you or others will be changed (e.g. the name of your workplace, friends, colleagues and venues attended). Original tape recordings will be securely locked in a filing cabinet and destroyed at the end of the project. Only the researcher will have access to the information collected. This information will be published to assist organisations who use peer education. In any publication, information will be provided in such a way that you cannot be identified.

Recompense to participants

In recognition of your contribution to this study and the effort you have made to attend this interview, we will recompense you with \$30 for travel expenses and other associated costs incurred as a result of your participation in this study. A \$10 recompense will be paid for the successful referrals you make to the study. There is an upper limit of 3 participants you can refer to the study.

Any complaints may be directed to the Ethics Secretariat, The University of New South Wales, SYDNEY 2052 AUSTRALIA (phone 9385 4234, fax 9385 6648, email ethics.sec@unsw.edu.au). Any complaint you make will be investigated promptly and you will be informed of the outcome.

Feedback to participants

Feedback about the results of the project will be provided through a project summary article in NUAA's Users News Magazine, journal articles, and conference presentations. The research's PhD thesis will be available in early 2012, and can be accessed via the NCHSR website: <http://nchsr.arts.unsw.edu.au>

Your consent

Your decision whether or not to participate will not prejudice your future relations with the University of New South Wales. If you decide to participate, you are free to withdraw your consent and to discontinue participation at any time without prejudice.

If you have any questions now, please feel free to ask the researcher. If you have any additional questions later, please contact Jamee Newland on (02) 9385 6397, or email Jamee.newland@student.unsw.edu.au

You will be given a copy of this form to keep.

Appendix E Participant socio-demographics

Name	Location	Gender	Age	Main drug injected	Self-reported HCV status
Sue *	Newcastle	F	16	Morphine	HCV -
Tim *	Newcastle	M	17	Morphine	HCV -
Jayde *	New-castle	F	17	Speed	HCV?
Chris *	Newcastle	M	21	Heroin	HCV -
Natasha	Newcastle	F	39	Heroin	HCV +
Mai *	South-West Sydney	F	24	Heroin	HCV -
Hao *	South-West Sydney	M	28	Heroin	HCV -
Tai *	South-West Sydney	M	27	Heroin	HCV +
Sarath *	South-West Sydney	M	28	Heroin	HCV -
Binh *	South-West Sydney	M	25	Heroin	HCV +
Dung *	South-West Sydney	M	32	Heroin	HCV -
Kevin *	South-East Sydney	M	47	OxyContin	HCV +
Toby *	South-East Sydney	M	22	Cocaine	HCV +
Catherine *	South-East Sydney	F	33	OxyContin	HCV +
Henry *	South-East Sydney	M	22	Cocaine	HCV +
Rebecca *	South-East Sydney	F	21	Speed	HCV?
Alison *	South-East Sydney	F	27	Heroin	HCV +
Ryan	South-East Sydney	M	21	Heroin	HCV-
Ruby	South-East Sydney	F	43	Speed	HCV+
James	South-East Sydney	M	42	Ice	HCV+
Josh	South-East Sydney	M	55	Heroin	HCV+
Jack	South-East Sydney	M	37	Heroin	HCV +
Kay	NSW North Coast	F	34	Heroin	HCV -
Terry	NSW North Coast	M	44	Heroin	HCV+
Sammy	NSW North Coast	F	45	Heroin	HCV+
Emma	NSW North Coast	F	43	Heroin	HCV-
Sid	NSW North Coast	M	24	Heroin	HCV-
Jules	NSW North Coast	M	27	Heroin	HCV-
Liam	NSW North Coast	M	46	Heroin	HCV-
Claire	NSW North Coast	F	34	Heroin	HCV +
Scott	NSW North Coast	M	42	Heroin	HCV ?
David	NSW North Coast	M	38	Methadone	HCV +
Paul	NSW North Coast	M	47	Heroin	HCV -

*indicated inclusion in social network analysis